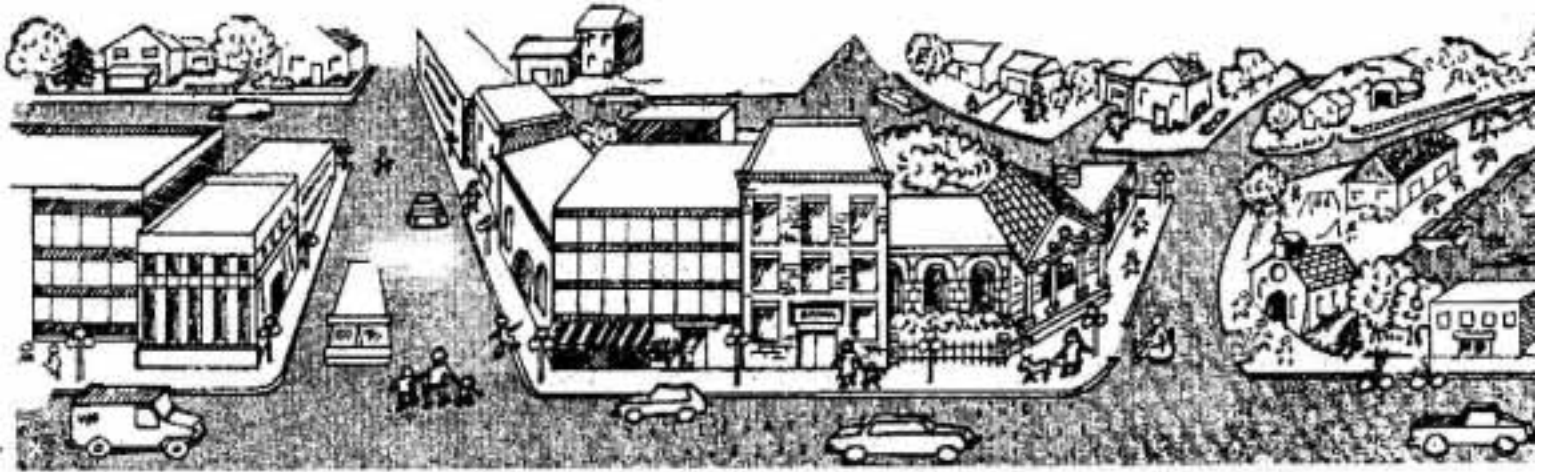


Pathways to Excellence



Copyright © 1993, Human Services Institute, Inc.

*All rights reserved. No part of this manual
may be reproduced without the expressed written
permission of the Human Services Institute.*

TABLE OF CONTENTS

	<u>PAGE</u>
Acknowledgements	i
Dedication	ii
About HSI	iii
About Pathways to Excellence	iv
PART ONE	1
• Historical Perspective	
• Current Reality	
PART TWO	50
• Framework for Excellence	
• Guiding Principles for Quality Human Services	
PART THREE	77
• Action for Empowerment	
• Discovering the Future	

Acknowledgement

*The content of the **Pathways to Excellence** training program has been inspired by the knowledge, experience and pioneering spirit of so many people whom we have worked with over the years. We would like to recognize the pioneering spirit of a few who, without even knowing it, have contributed significantly to this manual. They are Burton Blatt, Marc Gold, Gunnar Dybwad, Cory Moore, Bob Perske, Wolf Wolfensberger, John McKnight, John O'Brien, Connie Lyle-O'Brien, Beth Mount, Judith Snow, Jack Yates, Cathy Bartholomew-Lorimer and Guy Caruso.*

Dedication

Our work at HSI has been profoundly shaped by the life and beliefs of Jerry Kiracofe. He was a unique and special friend whose spirit continues to graciously and mindfully guide us in this work and everything we do.

About HSI

MISSION STATEMENT

The mission of the Human Services Institute is to work with a growing network of people toward the goal of full participation in community for people with disabilities. It is our objective to promote constructive action that will influence public attitudes, shape public policy, and redirect program resources. We hope to bring about changes by encouraging people who provide services to join with people who rely on services, and their families, to build the capacity of their communities to accept people with disabilities and include them in everyday community life.

PHILOSOPHY

People with disabilities, like everyone else, want homes, friends, and other meaningful ways to grow with dignity and enjoy life. Community is where these experiences of citizenship occur.

Being a part of the community means spending time in ordinary places, growing in relationships with others, having opportunities that draw on one's capacities, being able to make choices, and having those choices honored. Such everyday experiences afford people with disabilities the opportunity to enjoy a positive reputation through citizenship. If people need support to participate in the community, support should be available.

While there is reason to be hopeful about this goal, there is cause for much concern. Common human service practices are likely to be highly structured, inward-centered, and impersonal. As a result, these services tend to distance people from ordinary experiences of the community. This can make it difficult for people to accomplish the simple goal of community living. There is no quick fix for this ingrained human service pattern, but constructive action is possible.

The Human Service Institute encourages people with disabilities and those who are involved with people with disabilities to talk with each other. The Human Services Institute brings people together to share ideas, frustrations, and dreams in order to further mutual understanding and respect. We bring people together through conferences, workshops, seminars, and retreats. We offer training, consultation and support.

Anyone who shares our goals is welcome to join us.

About Pathways to Excellence

Pathways to **Excellence** is a way of professional and personal conduct of the highest quality and integrity that will lead to the empowerment of those who rely on you and your organization.

The key purpose of Pathways to **Excellence** training is to contribute to organizational excellence by building the professional capacity and personal commitment of individual participants. Organizational excellence depends on having employees who have balanced their knowledge and abilities with real dedication and caring. **Pathways to Excellence** is uniquely designed to help participants develop this balance by guiding them to:

- Reflect on the life patterns and conditions of people who rely on them or their organization each day.
- Explore key factors, past and present, that shape and influence these patterns and conditions.
- Learn a new way of thinking and acting that will open creative possibilities and opportunities for change.
- Build professional competence by learning practical strategies that work to improve the quality of life in community.
- Strengthen personal commitment by affirming the values and beliefs that are at the core of our community life and our professional roles.

By building professional competence and strengthening personal commitment, we will build organizational excellence directed toward improving the quality of life in our communities for all citizens.

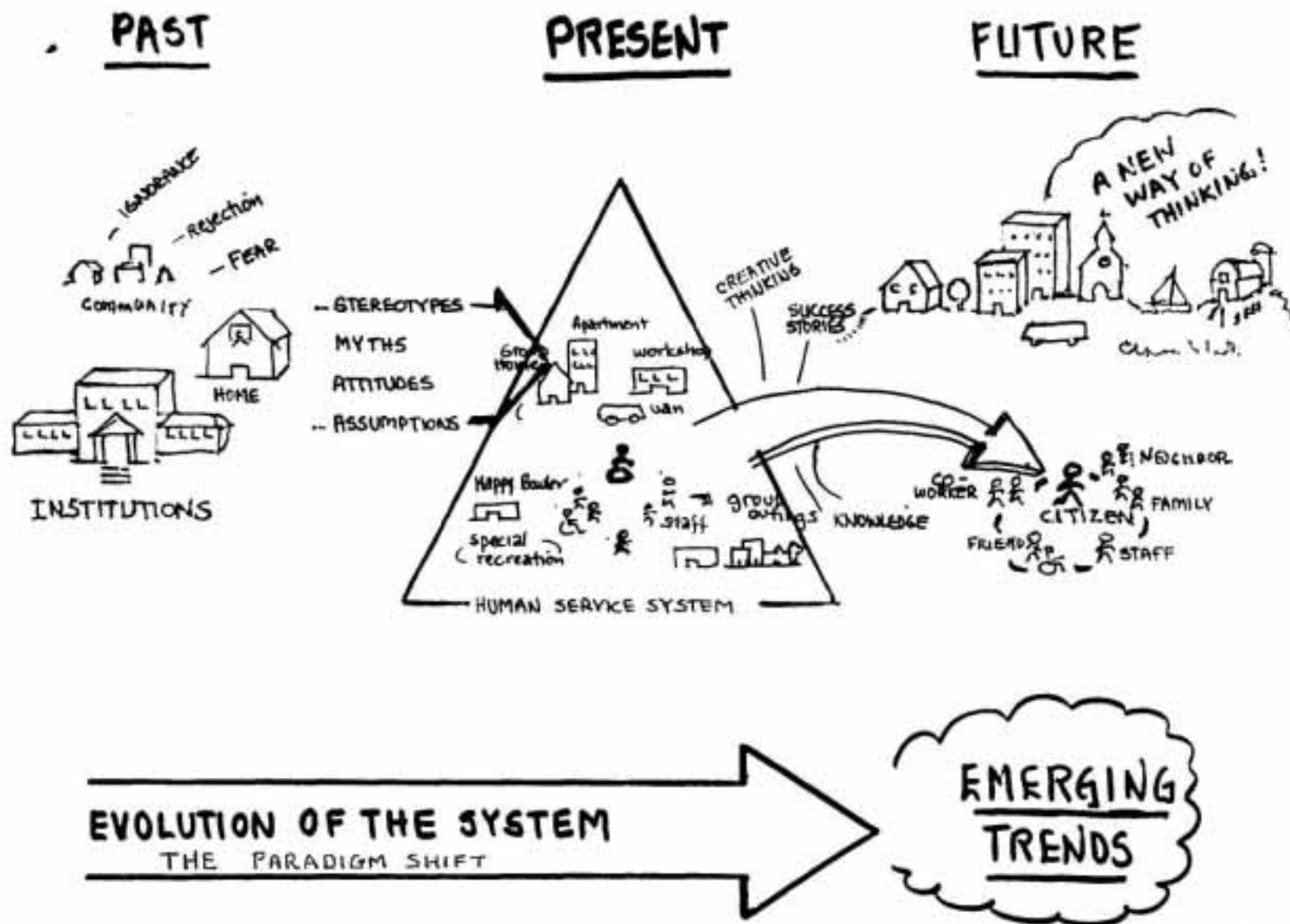
PART ONE:

The Current Reality

The Road to Clienthood

- The Paradigm Shift
- What's Life Like?
- Historical Context
- Critical Analysis of the Service System

A PATHWAY TO EXCELLENCE





What's Life Like?

Notes About the Program Where I Work:

Notes About People I Know:

Other Notes:

Common Experiences of Socially Devalued People

Notes:

LABELLED STEREOTYPED ROLES

REJECTED - EXCLUDED LONELY - LOSS

OF RELATIONSHIPS DISCONTINUITY

LOSS OF CONTROL AND AUTONOMY

DEPERSONALIZED - LOSS OF DIGNITY

POOR - UN(UNDER) EMPLOYED

BORED - LIFE WASTED

ABUSED AND NEGLECTED

PROGRAMMED AND TRAINED

IGNORED

Source: Wolf Wolfensberger

REMEMBER:

Life doesn't have to be this way for people with disabilities. In fact, we all probably know people with disabilities whose general life experiences do not fit these descriptors. However, society's myths, stereotypes and attitudes toward disabilities in general have led to these common experiences over time. Why is this?

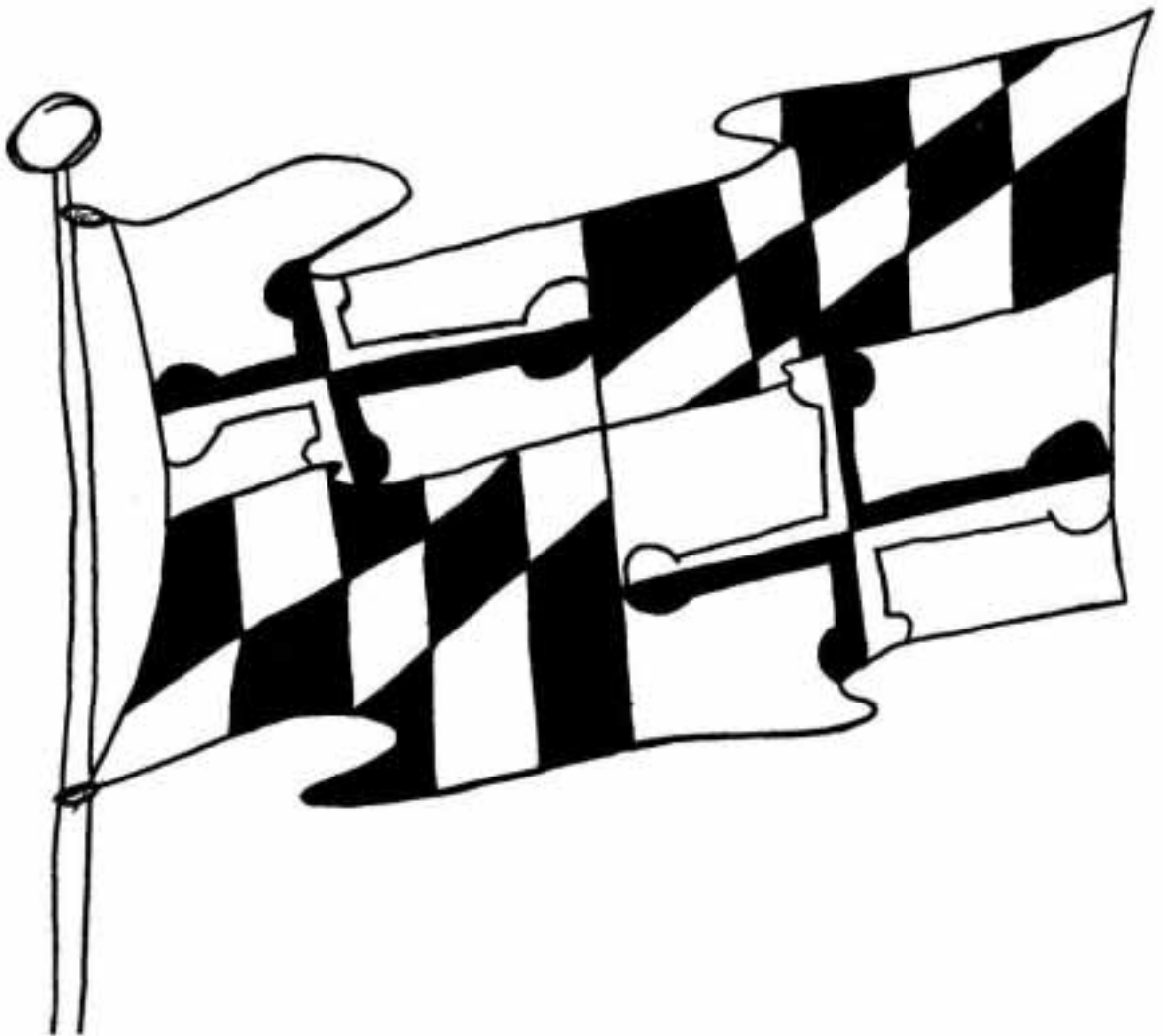
Overview: The History of Human Services

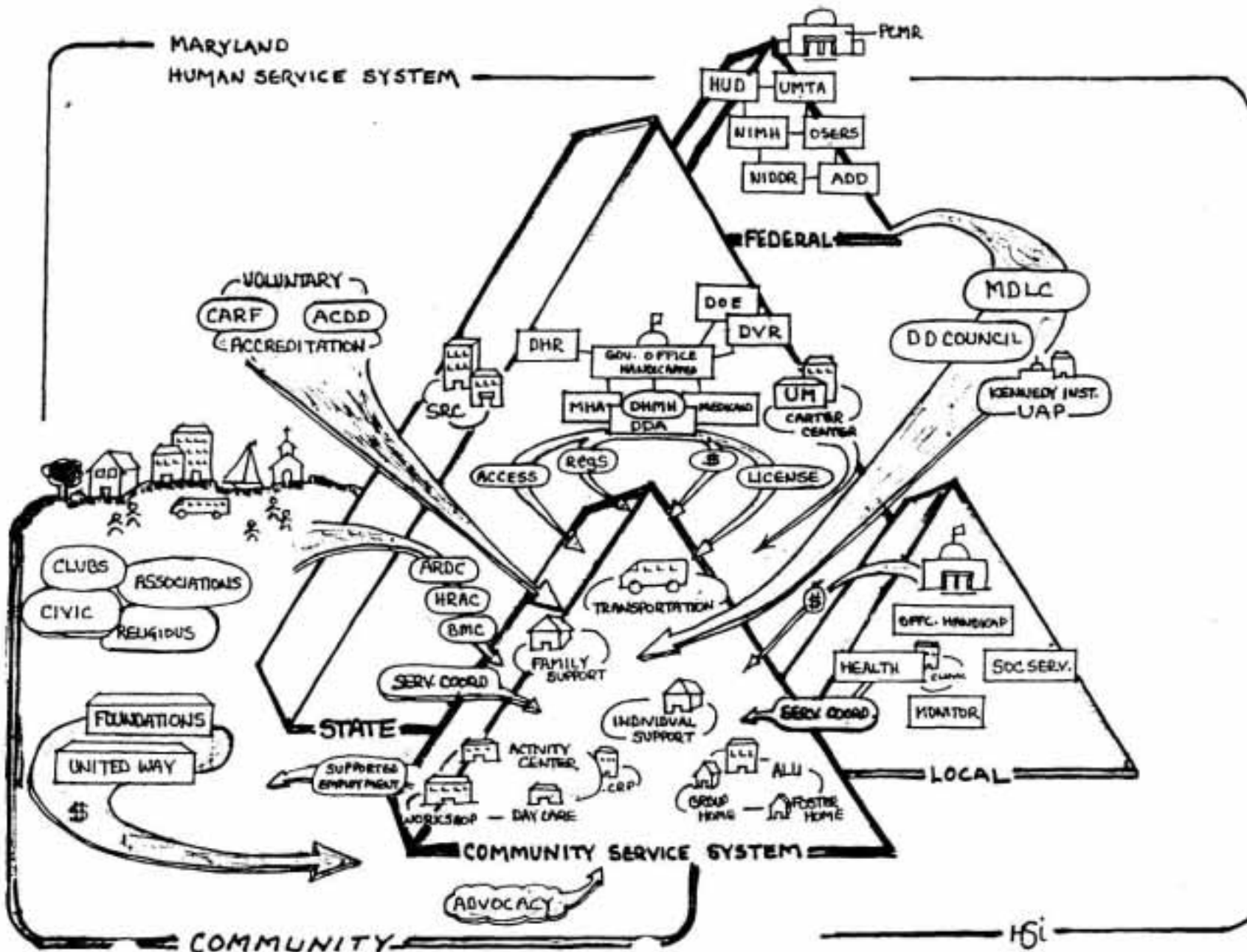
This is not intended to be a complete history ~ but rather a chronological flow - highlighting selected major influences.

NOTES:

1800	Wild Boy of Avero <ul style="list-style-type: none">• Itard
1840 - 1850	First public facility in the U. S. <ul style="list-style-type: none">• Dr. Samuel Howe
1850 - 1900	More public facilities <ul style="list-style-type: none">• Asylums, shelters and colonies
1910	Defining intelligence <ul style="list-style-type: none">• A. Binet, France
1912	The 'Kallikak' Family <ul style="list-style-type: none">• Henry Goddard
1912 - 1950	The Eugenic Scare <ul style="list-style-type: none">• 'Good blood' - 'Bad blood'
1950's	Parent Advocacy Movement (ARC)
1960's	Increase Advocacy <ul style="list-style-type: none">• Normalization - Scandinavia
1970's	<ul style="list-style-type: none">- Institution Expose- Beginning of Deinstitutionalization- Litigation
1980's	<ul style="list-style-type: none">- Expansion of Community Programs- Legislation- Social Role Valorization
1990's	Community Acceptance

The Maryland Human Service System





Glossary of Acronyms for State System Illustration

FEDERAL

ADD	Administration on Developmental Disabilities
NIDDR	National Institute for Developmental Disabilities Research
NIMH	National Institute of Mental Health
OSERS	Office of Special Education and Rehabilitation Service
UMTA	Urban Mass Transit Administration
HUD	Department of Housing and Urban Development

STATE

DOE	Department of Education
DORS	Division of Rehabilitation Services
DHR	Department of Human Resources
MHA	Mental Hygiene Administration
DHMH	Department of Health and Mental Hygiene
DDA	Developmental Disabilities Administration
U of M	University of Maryland — Carter Center
SRC	State Residential Centers

COMMUNITY SERVICE SYSTEM

ALU	Alternative Living Unit
CRP	Community Rehabilitation Program
ARDC	Admission Review and Discharge Committee
HRAC	Human Rights Advisory Committee
BMC	Behavior Management Committee

OTHER

DDC	Developmental Disabilities Council
UAP	University Affiliated Programs
MDLC	Maryland Disabilities Law Center
ACDD	Accreditation Council on Developmental Disabilities
CARF	Commission on Accreditation of Rehabilitation Facilities

DEVELOPMENTAL DISABILITIES ADMINISTRATION

PHILOSOPHY

- o Based on inherent belief in rights and dignity of the individual
- o All persons regardless of severity of handicapping condition are capable of growing, developing and learning
- o All individuals are valued and should be afforded the opportunity to take advantage of human, legal and social rights
- o Services should be provided in surroundings and through methods that are culturally normal
- o Services that are available for non-disabled citizens should be available for citizens with developmental disabilities
- o Opportunities should be available to form meaningful relationships to interact with non-disabled persons and for direct participation in decision-making

Department of Health and Mental Hygiene
Developmental Disabilities Administration
Fiscal Year 1994 Allowance

Community Based Programs

Residential Services Day and	117,442,241
Transportation Service Services	35,795,550
Coordination Purchase of Care	5,055,372
Summer Programs Family	5,380,892
Support Services Individual	294,840
Family Care Individual Support	807,922
Services Behavioral Support	2,289,484
Services Day Services- Waiver	11,265,406
Intensive Behavior Management	3,279,371
Community Supported Living	23,591,924
Prior Year Grant Activity	1,351,543
	2,111,655
Subtotal	1,000,000

209,666,200

Institutional Services

Rosewood Center	
Henryton Center Great	
Oaks Center Holly	37,249,487
Center Potomac Center	112,361
Brandenburg Center	22,628,050
	13,766,806
	8,948,492
Subtotal	3,473,391

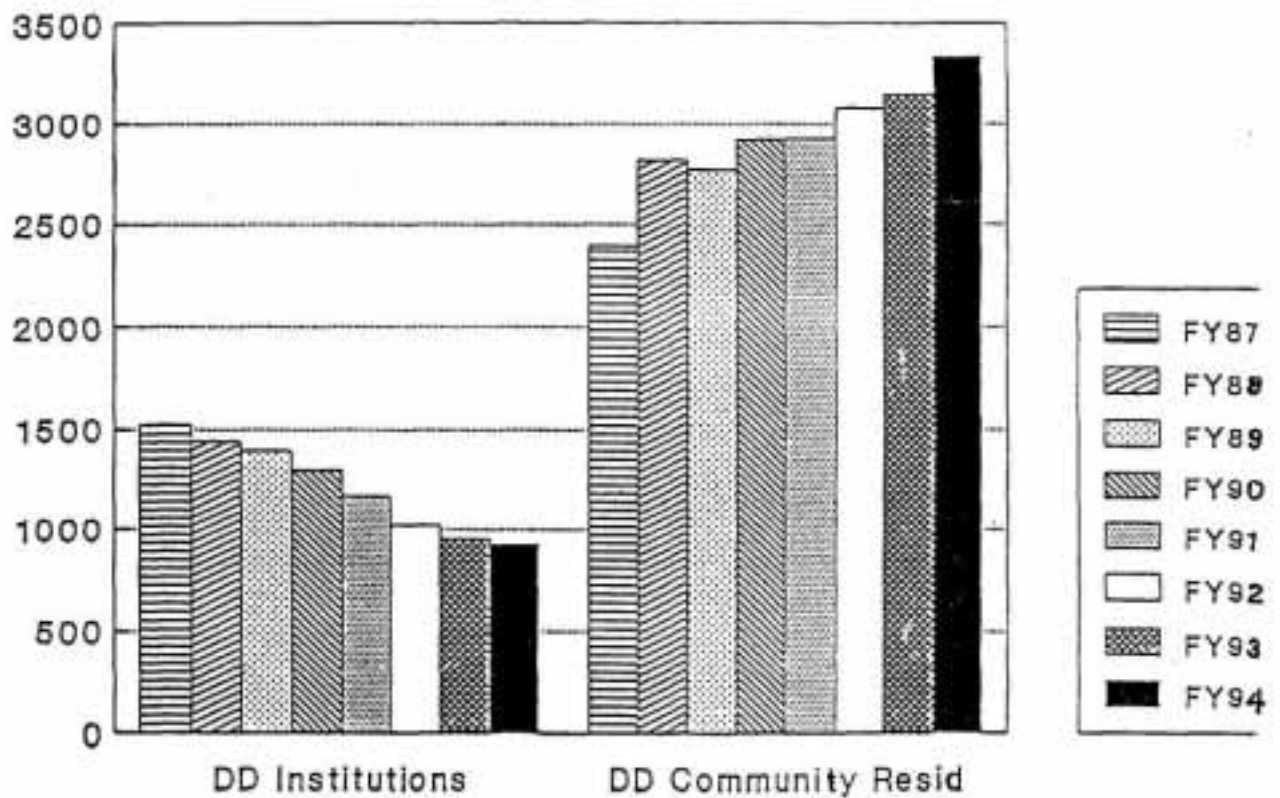
Administration 86,178,587

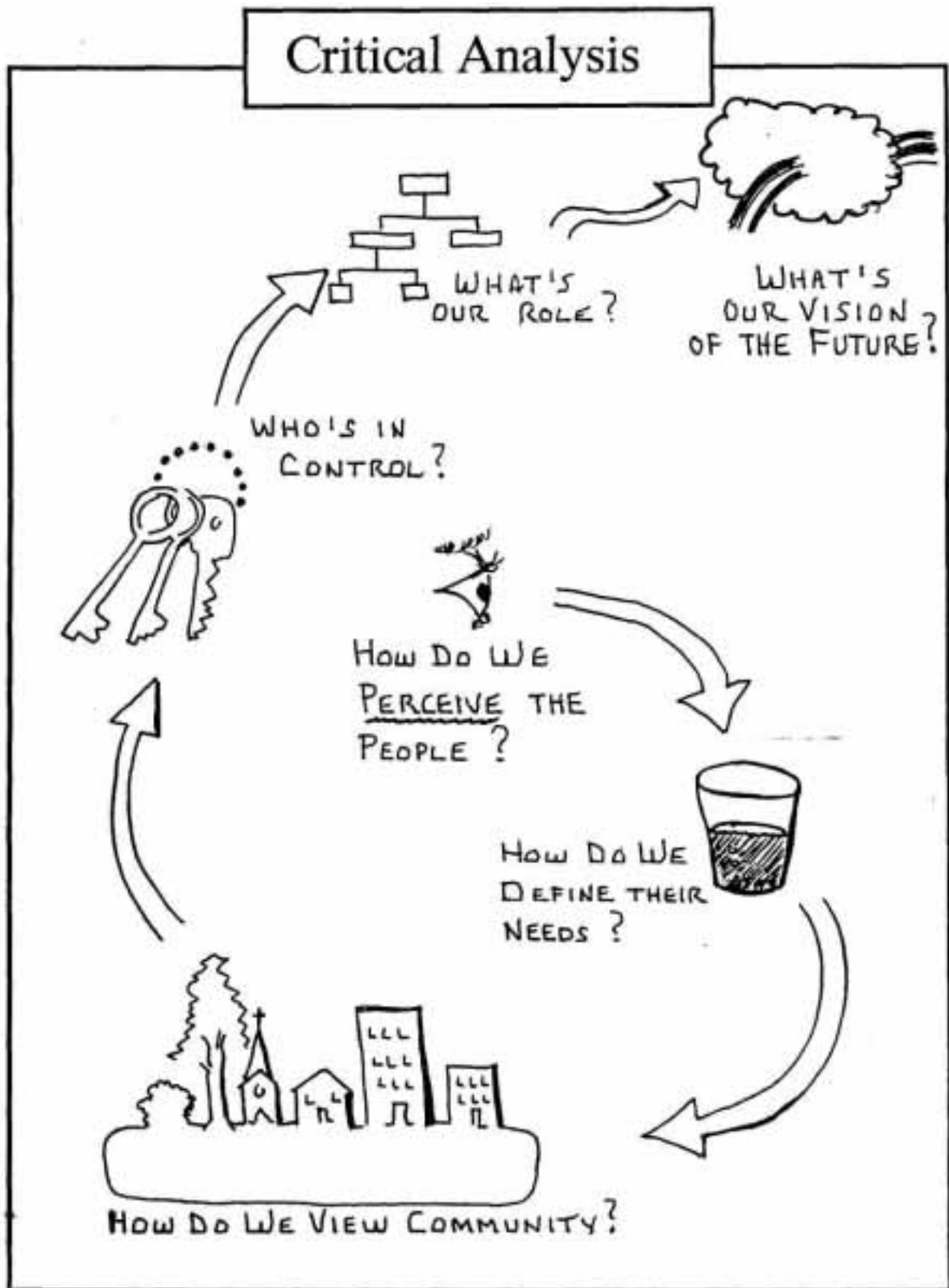
3,148,576

Grand Total

298,993,363

DEPARTMENT OF HEALTH AND MENTAL HYGIENE
DEVELOPMENTAL DISABILITIES ADMINISTRATION
INSTITUTION VS COMMUNITY POPULATIONS
FY 1987-FY 1994





QUESTION #1:



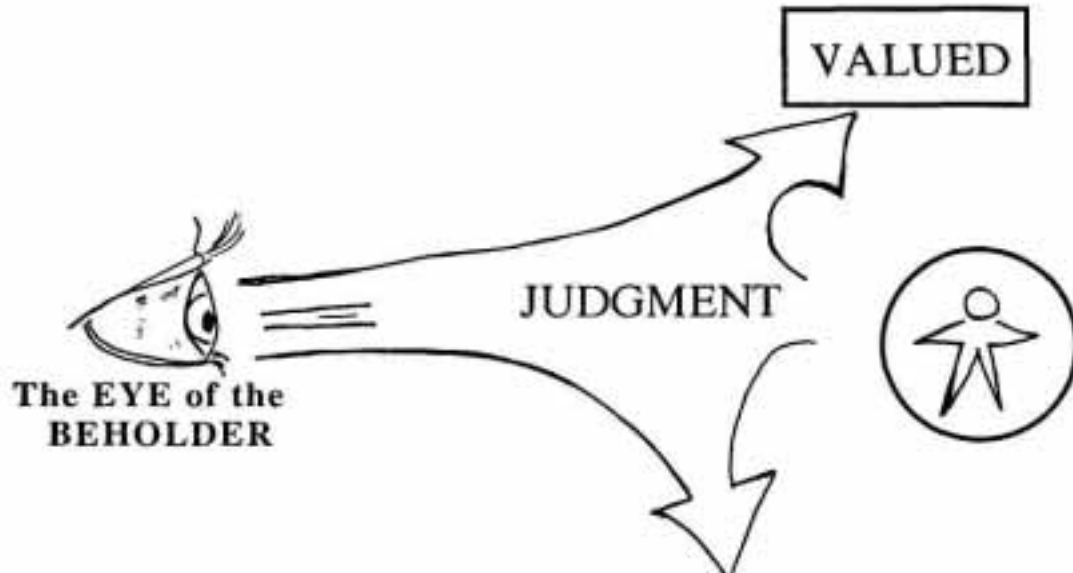
How do we perceive the people?

----- SOCIAL ROLE -----

"A socially expected behavior pattern, usually defined in order to facilitate the fulfillment of a particular function.

A socially expected behavior pattern usually assigned to, or assumed by an individual, and usually (partially) reflects the person's social status."

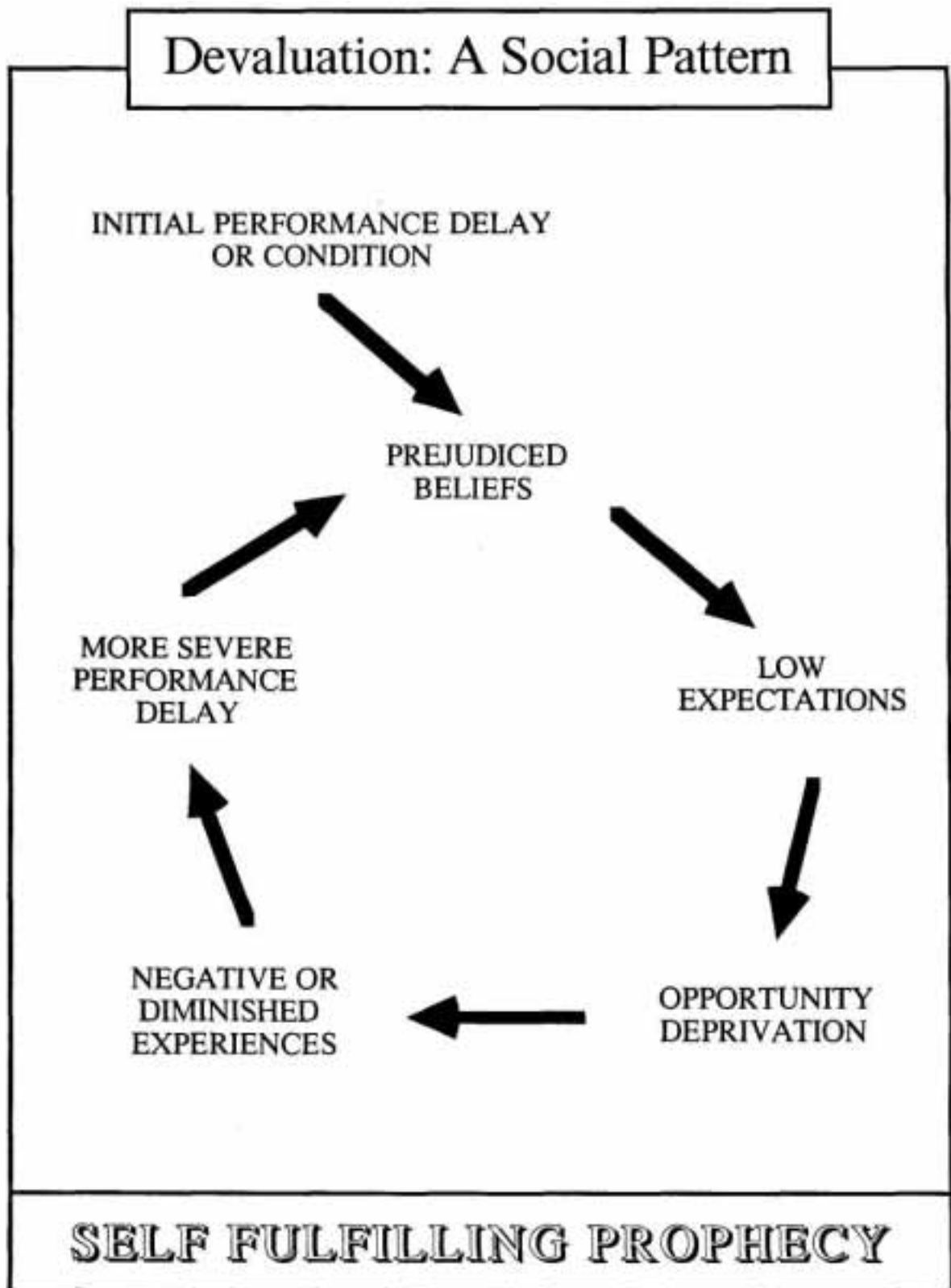
THE PHENOMENON OF DEVALUATION



A Person may be perceived as DEVALUED when...

- They are DIFFERENT from others
 - In one or more ways
 - The differences are seen as IMPORTANT
 - The differences are seen as NEGATIVE
-

Personal Reflection:



CLIENTHOOD:

Being defined by your disability label

LABELING

prevents us from seeing and treating the people so defined as human beings with feelings, understandings and needs...we lose the ability...to see the world from their point of view.

*Bogdan & Taylor (1982)
Inside Out: The Social Meaning
of Mental Retardation*

Notes:

Watch your language!

No No's for the media regarding the disabled.

AFFLICTED—Very negative and a definite downer! Person *who has or is affected by* is much better.

CEREBRAL PALSIED—Sounds like an inanimate object instead of a person. Why not *person or people with cerebral palsy*?

C.P.—OK to describe the condition but NOT a person. This puts all people in a neat little package and deposits them in a file drawer. Please use *who has or who have cerebral palsy* when referring to people.

CRIPPLED OR CRIPPLER—This paints a mental picture no one wants to look at.

DISEASE—Cerebral palsy is NOT a disease. People with cerebral palsy are as healthy as anybody else. Better to say *condition*.

DRAIN AND BURDEN—We wouldn't touch these two words with a 10-foot pole. *Added responsibility* is much better.

POOR—Physical handicaps have nothing to do with how wealthy someone is. Love and self-esteem are priceless qualities. A person's character determines the richness of his or her life.

SUFFERS FROM—If someone with a disability is independent and copes with life as well as most of us, then this phrase definitely doesn't apply.

UNFORTUNATE—What's unfortunate is that this word is often used to describe people with physical disabilities. Don't offend with this one.

VICTIM—A person with physical disabilities was neither sabotaged nor necessarily in a plane, train or car crash. There's no way to rephrase this turkey.

WHEELCHAIRBOUND—Leaves the impression that the *wheelchair user*—a better descriptive term—is glued to his or her transportation.

This List is provided as a public service.

Your help is needed to keep people with cerebral palsy—or with other disabling conditions—from sounding pitiful, inhuman or like beings from outer space in your stories.

People with cerebral palsy and other disabilities have the same rights as everyone else in this world—the right to fall in love, to marry, to hold down a competitive job, to acquire an adequate and appropriate education. Above all, they have a right to self-esteem.

Please insure these rights by referring to the disabled in terms that acknowledge ability, merit, dignity. In turn, we hope your readers and listeners will follow suit.

For a *(act sheet and other information on cerebral palsy, contact:*

Public Relations Department
United Cerebral Palsy Associations, Inc.
66 East 34th Street
New York, N.Y. 10016
(212) 481-6344



UNITED CEREBRAL PALSY

Improving the Quality of Life for
the Abled and Disabled

Definition of Developmental Disability P.L. 100-146

The term '*developmental disability*' means a severe, chronic disability of a person which:

- a. is attributable to a mental or physical impairment or combination of mental and physical impairments;
- b. is manifested before the person attains age twenty-two;
- c. is likely to continue indefinitely;
- d. results in substantial functional limitations in three or more of the following areas of major life activity:
 - (i) self-care,
 - (ii) receptive and expressive language,
 - (iii) learning,
 - (iv) mobility,
 - (v) self-direction,
 - (vi) capacity for independent living, and
 - (vii) economic self-sufficiency; and
- e. reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment or other services which are of lifelong or extended duration and are individually planned and coordinated.

Facts About Mental Retardation

INTRODUCTION TO MENTAL RETARDATION

What is mental retardation?

People with mental retardation mature intellectually at a below-average rate and experience unusual difficulty in learning, social adjustment and economic productivity.

Mental retardation is not a disease, nor should it be confused with mental illness. Children with mental retardation grow into adults with mental retardation; they do not remain "eternal children." The big difference is that they learn more slowly and with much greater difficulty.

The most generally accepted technical definition describes mental retardation as "significantly sub average general intellectual functioning existing concurrently with deficits in adaptive behavior, and manifested during the developmental period." In terms of IQ, individuals with mental retardation score below 70.

How prevalent is the condition?

People with mental retardation constitute one of America's largest groups of citizens having disabilities. They include more than 7.5 million people, and slightly more than 125,000 newborn children are added to this group each year. Today, one out of every 10 Americans has a family member with mental retardation.

Mental retardation is four times more common than rheumatic heart disease and nine times more prevalent than cerebral palsy. It affects 15 times as many people as total blindness.

Who are people with mental retardation?

Mental retardation cuts across the lines of race, educational, social and economic background. It can occur in anyone. As a matter of fact, hereditary components are known to account for only a fraction of the cases of mental retardation.

What are the causes of mental retardation?

Mental retardation can be caused by any condition which impairs development of the brain before birth, during birth or in the early childhood years. Well over 350 causes have already been discovered, but they account for only about one-fourth of all known mental retardation. In three-fourths of the cases, the specific cause remains unknown.

Some of the most common causes include:

- o **Genetic conditions** — These result from abnormality of genes inherited from parents, errors when genes combine, or from other disorders of the genes caused during pregnancy by infections, over exposure to x-rays and other factors. Inborn errors of metabolism which may produce mental retardation, such as PKU [phenylketonuria], fall in this category. Chromosomal abnormalities have likewise been related to some forms of mental retardation, such as Down syndrome.
- o **Problems during pregnancy**— Use of alcohol or drugs by the pregnant mother may be the largest preventable cause of mental retardation. Adolescent pregnancy is also linked to mental retardation, partially because of poor prenatal care and frequency of premature births in teen-agers. Malnutrition, Rubella, glandular disorders and diabetes, Cytomegalovirus, and many other illnesses of the mother during pregnancy may result in a child being born with mental retardation. Physical malformations of the brain or other organs originating in prenatal life may also result in mental retardation.
- o **Problems at birth** — Although any birth condition of unusual stress may injure the infant's brain, prematurity and low birth weight predict serious problems more often than any other conditions.
- o **Problems after birth** — Childhood diseases such as whooping cough, chicken pox, measles, meningitis and encephalitis can damage the brain, as can accidents such as a blow to the head or near drowning. Glandular imbalance or malnutrition may prevent normal development, while substances such as lead and mercury can produce irreparable damage to the brain and nervous system.
- o **Poverty and cultural deprivation** — Children in poor families may become mentally retarded because of malnutrition, disease-producing conditions, inadequate medical care and other hazards in their environment affecting health, such as lead poisoning. Also, children in disadvantaged areas are likely to be deprived of many common cultural and day-to-day experiences of other youngsters. Research suggests that such understimulation can result in irreversible damage and can serve as a cause of mental retardation.

What are the degrees of mental retardation?

About 89 percent of people with mental retardation are mildly retarded and in many respects, quite similar to people without retardation. They differ primarily in rate and degree of intellectual development. While still young, their mental retardation is not readily apparent, and these children are not usually identified as retarded until they enter public school.

National Headquarters, 500 E. Border St, S-300, Arlington, Texas 76010, 817/261-6003 817/277-0553(TDD)

More Facts About Mental Retardation

People with moderate mental retardation comprise about 6 percent of the population of people with mental retardation and are more obviously handicapped. Their retardation is usually apparent before school age. However, appropriate educational opportunities throughout the developmental years can prepare these individuals for satisfying and productive lives in the community.

The remaining 5 percent of people with mental retardation are severely or profoundly retarded. In addition to the obvious intellectual impairment, they frequently have other handicaps — cerebral palsy, epilepsy, blindness or deafness. Technological advances have demonstrated that most people who are severely and profoundly retarded can learn to care for their basic needs. They also can perform many useful work activities, with supervision, and can otherwise adapt satisfactorily to normal patterns of life.

ESTIMATES OF RETARDATION BY **ACE** AND DEGREE

1990 Estimate	All Ages	Under 21	Over 20
General Population	248.7 mil.	75.3 mil.	173.4 mil.
3% general population	7.5 mil.	2.3 mil.	5.2 mil.
Mental Retardation Levels			
Profound (IQ under 20) approx. 1 1/2%	112.5 thou.	34.5 thou.	70 thou.
Severe (IQ 21-35) approx. 3 1/2%	262.5 thou.	80.5 thou.	182 thou.
Moderate (IQ 36-50) approx. 6%	450 thou.	138 thou.	312 thou.
Mild (IQ 51-70) approx. 89%	6.7 mil.	2.1 mil.	4.6 mil.

Can mental retardation be ameliorated?

All individuals who are mentally retarded have the capacity to learn, develop and grow. The great majority can become economically productive, fully participating members of society. They should be integrated fully into the ordinary life of their communities, as integration enhances their opportunities for human development. This means that children should be educated in their neighborhood schools with their friends, receive an education that will prepare them to live and work in the real world and play and participate in recreational activities with non-disabled peers. Adults should engage in work and be paid for it, choose

where and with whom they live, and participate in the recreational life of the community.

While many people with mental retardation will utilize the same community services as other community residents, some will require specialized services and supports to meet their individual needs. There is a serious lack of such services and supports throughout the country. Filling this gap can also contribute to the amelioration of mental retardation.

Can mental retardation be prevented?

Some authorities conclude that 50 percent of mental retardation cases could be prevented if current knowledge were fully implemented toward assuring the healthy birth and development of babies and young children. Examples of approaches to prevention include:

- o better prenatal care and better education in family planning for youths to prevent mental retardation caused by conditions associated with adolescent pregnancy, such as low birth weight and premature birth;
- o routine screening and immunization of the mother before transfusions, miscarriage, or childbirth to prevent mental retardation caused by Rh Hemolytic Disease;
- o the availability and provision of immunization against Rubella, measles and other contagious disease prior to pregnancy;
- o the availability and provision of genetic counseling;
- o increased educational programs and materials on the risks of exposure of the fetus to dangers such as X-rays, smoking, alcohol and drug use, non-prescription medications and prescribed medications;
- o adequate and available prenatal care, including nutrition;
- o education regarding the impact of sexually transmitted diseases on the unborn fetus;
- o mandatory funded newborn screening programs for metabolic disorders such as phenylketonuria, galactosemia and hypothyroidism;
- o mandatory use of seat belts, safety seats and helmets;
- o education regarding the risks of the use of aspirin with children;
- o availability of competent perinatal and post natal care, including frequent physical/developmental checks and adequate nutrition;
- o mandatory immunization of children for all preventable, contagious diseases;
- o education designed to prevent childhood injuries such as falls, drownings and poisoning;
- o removal of environmental contaminants which lead to conditions such as lead poisoning;
- o enforcement of existing public policy (i.e. prohibition of lead based products).

Facts About Down Syndrome

DOWN SYNDROME

by Siegfried M. Pueschel, M.D., Ph.D., M.P.H.

What is Down syndrome?

People with Down syndrome are first and foremost human beings who have recognizable physical characteristics and limited intellectual endowment which are due to the presence of an extra chromosome 21.

The estimated incidence of Down syndrome is between 1 in 1,000 to 1 in 1,100 live births. Each year approximately 3,000 to 5,000 children are born with this chromosome disorder. It is believed there are about 250,000 families in the United States who are affected by Down syndrome.

How do children with Down syndrome develop?

Children with Down syndrome are usually smaller, and their physical and mental developments are slower, than youngsters who do not have Down syndrome. The majority of children with Down syndrome function in the mild to moderate range of mental retardation. However, some children are not mentally retarded at all; they may function in the borderline to low average range; others may be severely mentally retarded. There is a wide variation in mental abilities and developmental progress in children with Down syndrome. Also, their motor development is slow; and instead of walking by 12 to 14 months as other children do, children with Down syndrome usually learn to walk between 15 to 36 months. Language development is also markedly delayed.

It is important to note that a caring and enriching home environment, early intervention, and integrated education efforts will have a positive influence on the child's development.

What are the physical features of a child with Down syndrome?

Although individuals with Down syndrome have distinct physical characteristics, generally they are more similar to the average person in the community than they are different. The physical features are important to the physician in making the clinical diagnosis, but no emphasis should be put on those characteristics otherwise. Not every child with Down syndrome has all the characteristics; some may only have a few, and others may show most of the signs of Down syndrome. Some of the physical features in children with Down syndrome include flattening of the back of the head, slanting of the eyelids, small skin folds at the inner corner of the eyes, depressed nasal bridge, slightly smaller ears, small mouth, decreased muscle tone, loose ligaments, and small hands and feet. About fifty percent of all children have one line across the palm, and there is often a gap between the first and second toes. The physical features observed in children with Down syndrome (and there are many more than described above) usually do not cause any disability in the child.

How many chromosome subtypes are observed in Down syndrome?

There are three main types of chromosome abnormalities in Down syndrome:

The vast majority of children with Down syndrome (approximately 95 percent) have an extra 21 chromosome. Instead of the normal number of 46 chromosomes in each cell, the individual with Down syndrome has 47 chromosomes. This condition is called trisomy 21.

The second type is called translocation since the extra 21 chromosome is attached or translocated on to another chromosome, usually on chromosome 14, 21 or 22. If translocation is found in a child with Down syndrome, it is important to examine the parents' chromosomes, since in at least one-third of the cases, a parent may be a carrier of the translocation. This form of chromosome error is found in 3 - 4 percent of the individuals with Down syndrome.

Another chromosome problem, called mosaicism, is noted in about 1 percent of individuals with Down syndrome. In this case, some cells have 47 chromosomes and others have 46 chromosomes. Mosaicism is thought to be the result of an error in cell division soon after conception.

What is the cause of Down syndrome?

Although many theories have been developed, it is not known what actually causes Down syndrome. Some professionals believe that hormonal abnormalities, X-rays, viral infections, immunologic problems, or genetic predisposition may be the cause of the improper cell division resulting in Down syndrome.

It has been known for some time that the risk of having a child with Down syndrome increases with advancing age of the mother, i.e., the older the mother, the greater the possibility that she may have a child with Down syndrome. However, most babies with Down syndrome (more than 85 percent) are born to mothers younger than 35 years. Some investigators reported that older fathers may also be at an increased risk of having a child with Down syndrome.

It is well known that the extra chromosome in trisomy 21 could either originate in the mother or the father. Most often, however, the extra chromosome is coming from the mother.

What kind of information can be provided through genetic counseling?

Parents who have a child with Down syndrome have an increased risk of having another child with Down syndrome in future pregnancies. It is estimated that the risk of having another child with Down syndrome is about one in 100 in trisomy 21 and mosaicism. If, however, the child has translocation Down syndrome and if one of the parents is a translocation carrier, then the risk of recurrence increases markedly. The actual risk depends on the type of translocation and whether the translocation is carried by the father or the mother.

National Headquarters, 500 E. Border St, S-300, Arlington, Texas 76010, 817/261-6003 817/277-0553(TDD)

More Facts About Down Syndrome

What health concerns are often observed in people with Down syndrome?

The child with Down syndrome is in need of the same kind of medical care as any other child. The pediatrician or family physician should provide general health maintenance, immunizations, attend to medical emergencies, and offer support and counseling to the family. There are, however, situations when children with Down syndrome need special attention:

1. Sixty to 80 percent of children with Down syndrome have hearing deficits. Therefore, audio logic assessments at an early age and follow-up hearing tests are indicated. If there is a significant hearing loss, the child should be seen by an ear, nose and throat specialist.
2. Forty to 45 percent of children with Down syndrome have congenital heart disease. Many of these children will have to undergo cardiac surgery and often will need long term care by a pediatric cardiologist.
3. Intestinal abnormalities also occur at a higher frequency in children with Down syndrome. For example, a blockage of the food pipe (esophagus), small bowel (duodenum), and at the anus are not uncommon in infants with Down syndrome. These may need to be surgically corrected at once in order to have a normal functioning intestinal tract.
4. Children with Down syndrome often have more eye problems than other children who do not have this chromosomal disorder. For example, 3 percent of infants with Down syndrome have cataracts. They need to be removed surgically. Other eye problems such as cross-eye (strabismus), near-sightedness, far-sightedness and other eye conditions are frequently observed in children with Down syndrome.
5. Another concern relates to nutritional aspects. Some children with Down syndrome, in particular those with severe heart disease often fail to thrive in infancy. On the other hand, obesity is often noted during adolescence and early adulthood. These conditions can be prevented by providing appropriate nutritional counseling and anticipatory dietary guidance.
6. Thyroid dysfunctions are more common in children with Down syndrome than in normal children. Between 15 and 20 percent of children with Down syndrome have hypothyroidism. It is important to identify individuals with Down syndrome who have thyroid disorders since hypothyroidism may compromise normal central nervous system functioning.
7. Skeletal problems have also been noted at a higher frequency in children with Down syndrome, including kneecap subluxation (incomplete or partial dislocation), hip dislocation, and atlantoaxial instability. The latter condition occurs when the first two neck bones are not well aligned because of the presence of loose ligaments. Approximately 15 percent of people with Down syndrome have atlantoaxial instability. Most of these individuals, however, do not have any symptoms, and only 1 - 2 percent of individuals with Down syndrome have a serious neck problem that requires surgical intervention.
8. Other important medical aspects in Down syndrome, including immunologic concerns, leukemia, Alzheimer disease, seizure disorders, sleep apnea and skin disorders, may require the attention of specialists in their respective fields.

Can Down syndrome be medically treated?

Although many medications and various therapies have been touted as treatment for people with Down syndrome, there is no effective medical treatment available at the present time. However, recent advances in molecular biology make it feasible now to examine the genetic basis for Down syndrome. Once we identify the genes on chromosome 21 (many already have been discovered) and once we find the mechanism of how these genes interfere with normal developmental sequences, and if one could counteract these specific actions, a rational approach to medical therapy could emerge.

What educational services and vocational opportunities are available for people with Down syndrome?

Today early intervention programs, pre-school nurseries, and integrated special education strategies have demonstrated that youngsters with Down syndrome can participate in many learning experiences which can positively influence their overall functioning. Research has shown that early intervention, environmental enrichment, and assistance to the families will result in progress that is usually not achieved by those infants who have not had such educational and stimulating experiences.

Children with Down syndrome, like all children, can benefit from sensory stimulation, specific exercises involving gross and fine motor activities, and instruction in cognitive development. Also, preschool nurseries play an important role in the young child's life since exploring the environment beyond the home enables the child to participate in a broader world.

Later, the school can give the child a foundation for life through the development of academic skills and physical as well as social abilities. Experiences provided in school assist the child in obtaining a feeling of self-respect and enjoyment. School should provide an opportunity for the child to engage in sharing relationships with others and help to prepare the child to become a productive citizen. Contrary to some views, all children can learn, and they will benefit from placement in a normalized setting with support as needed.

During adolescence, youngsters with Down syndrome should be exposed to prevocational training in order to learn good work habits and to engage in proper relationships with co-workers. Appropriate vocational counseling and job training will result in meaningful employment, and this, in turn, should lead to a feeling of self-worth and of making a contribution to society.

What attitude should society have?

It is important that society develop attitudes that will permit people with Down syndrome to participate in community life and to be accepted. They should be offered a status that observes their rights and privileges as citizens, and in a real sense preserves their human dignity. When accorded their rights and treated with dignity, people with Down syndrome will, in turn, provide society with a most valuable humanizing influence.

Dr. Pueschel, Director, Child Development Center, Rhode Island Hospital, Providence, Rhode Island was awarded The Arc's 1990 Distinguished Research Award.

March 1992

Autism Fact Sheet

What is autism?

Autism is a severely incapacitating, lifelong developmental disability that begins at birth or during the first 3 years of life. It occurs in approximately 5 of every 10,000 births. The incidence is three times greater if a broader definition of autism is used. In the broader category would be both people with classical autism and others with varying degrees of autistic behavior. Autism is three times more common in males than females, and has been found throughout the world in families of all racial, ethnic, and social backgrounds.

What are the symptoms of autism?

- Slow development or lack of physical, social, and learning skills.
- Immature rhythms of speech, limited understanding of ideas, and use of words without attaching the usual meaning to them.
- Abnormal responses to sensations. Sight hearing, touch, pain, balance, smell, taste, the way a child holds his body—any one or a combination of these responses may be affected. (See illustrations on back panel)
- Abnormal ways of relating to people, objects and events.

Approximately 60% of all those with autism have I.Q. scores below 50; 20% between 50 and 70; and 20% greater than 70. Most show wide variations in performance on different tests at different times. Many children with autism have distinct skills in music, mathematics, or in using spatial concepts (for example, working jigsaw puzzles), but manifest severe retardation in other areas.

What causes autism?

There appear to be several possible causes, either alone or in combination with others. Among these are untreated phenylketonuria, rubella, celiac disease, and chemical exposure in pregnancy. Biochemical imbalance and genetic predisposition have also emerged as possible causes. No known factors in the

psychological environment of a child have been shown to cause autism.

How is it diagnosed?

Because there are no medical tests for autism at present, the diagnosis must be based on observations of the child's behavior. Sometimes the process of elimination is the only guide. For older children, whose early symptoms have changed, it may be necessary to interview the parents about the child's early years in order to avoid misdiagnosis.

Is autism ever associated with other disorders?

Autism occurs either by itself or in association with other disorders which affect brain function. Perinatal viral infections, some metabolic disturbances, epilepsy, or mental retardation may result in, or exist in conjunction with autistic behavior.

How severe can autism be?

In milder forms, autism most resembles a learning disability such as childhood aphasia. Usually, however, people with autism are substantially handicapped.

With approximately 3% of those afflicted, severe autism may cause extreme forms of self-injurious, repetitive, highly unusual, and aggressive behavior. The behavior may persist and be very difficult to change, posing a tremendous challenge to those who must manage, treat, and teach individuals with autism.

People with autism live normal life spans. Since certain symptoms may change or even disappear over time, persons with autism should be reevaluated periodically and their treatment adjusted to meet their changing needs.

What are the most effective treatments?

Various methods of treatment have been tried but no single treatment is effective in all cases. However, appropriate programming, based on individual functioning level and need, is of prime importance. There is no known cure.

More Facts About Autism

Education. Highly structured, skill-oriented training, tailored to the individual, has proven most helpful. Social and language skills should be developed as much as possible. Thought must also be given to avoiding secondary handicaps, such as loss of muscle tone when inactivity is a problem.

Counseling. Supportive counseling may be helpful for families with members who have autism, just as it is for other families with members who have lifelong disabilities. Physicians can usually advise parents as to counseling services available. Care must be taken to avoid unenlightened counselors who erroneously believe that parental attitudes and behavior cause autism.

Medication/Diet. In the types of autism where metabolic abnormalities can be identified, controlled diet and/or medication can be beneficial. Examples are those whose autism is caused by an excess of uric acid in the blood, or whose autism is aggravated by nutritional imbalances. Also, properly monitored medication to decrease specific symptoms can help some autistic individuals live more satisfactory lives.

What research is being done?

The National Institute of Neurological and Communicative Disorders and Stroke (NINCDS) initiated a research section on autism in 1983, and may be contacted directly concerning research initiatives in diagnostic, treatment, educational, habilitative, and evaluative approaches relevant to autism.

NINCDS is continuing to study the 14 autistic children identified in its Collaborative Perinatal Project (a 15-year study of 55,000 pregnancies and the outcomes). This project centers on efforts to identify predictive signs of autism.

Ongoing study is necessary to determine how autism occurs and to identify ways to prevent or alleviate its effects. Basic research in a broad spectrum of scientific disciplines is needed to shed further light on the challenges presented by Autism.

AUTISM:



NOTE: persons with autism may possess the above characteristics in various combinations and in varying degrees of severity.

Autism Society of America, Inc.*

Suite 503
8601 Georgia Avenue
Silver Spring, MD 20910
(301)565-0433
FAX 301/565-0834

*Formerly NSAC. The National Society for Children and Adults With Autism

How can I learn more?

The information and Referral Service at the Autism Society of America, Inc. can provide reading lists and film lists, and will answer questions. Following are some recommended publications, which can be obtained through our national office along with a comprehensive list of other appropriate references.

Cerebral Palsy Facts

What Is Cerebral Palsy?

Cerebral palsy is a group of conditions — not a disease — characterized by nerve and muscle dysfunction. Sometimes it shows itself by awkwardness of gait, loss of manual dexterity or other motor problems. Other disabilities may be seizures; vision, hearing, speech and learning difficulties; or psychological and behavioral problems.

What Causes Cerebral Palsy?

Cerebral palsy is caused by damage to the part of the brain that controls and coordinates muscular action. Most often it occurs during pregnancy, labor or shortly following birth. This can happen if the mother is in poor health, undernourished, smokes or consumes alcohol, or contracts certain viral infections early in pregnancy. It can also result from blood type incompatibility between parents, untreated jaundice of the newborn, adverse effects of medications and other factors such as premature birth.

In infants and young children brain damage from an accident or child abuse can cause cerebral palsy; so can lead poisoning from swallowing bits of lead paint.

Can It Be Prevented?

Cerebral palsy as a birth injury frequently can be prevented. One important preventive measure is care for the health of pregnant women. During pregnancy women should exercise good prenatal and health practices and avoid exposure to medications and X-rays unless monitored by a physician. Control of diabetes and anemia are important. Blood incompatibility between parents causes no problem with first pregnancies, but subsequent babies should be protected by immunizing an Rh negative mother with Rogam immediately after each pregnancy.

How Can It Be Detected?

The infant with cerebral palsy may be tense or irritable, feed poorly or have difficulty sucking. Often the first sign of trouble is abnormally slow development of the infant's muscular control and coordination. Other physical signs may be more obscure, so routine physical examinations during childhood are important. If cerebral palsy is diagnosed early, prompt treatment and training can reduce the extent of the disability.

What About Cure?

Cerebral palsy cannot be cured in the accepted sense at present, but considerable knowledge is at hand to assist in managing

the condition and controlling some of its effects. This means that many persons with cerebral palsy can join the mainstream of society and lead full and productive lives.

How Is It Managed?

In managing cerebral palsy in children the emphasis is on helping the child's growth and development. Physical, occupational, speech and hearing therapy provided by skilled professional personnel are important features of the program.

In some cases, either in a child or an adult, orthopedic or neurologic surgery may help to improve muscle coordination. Braces may reinforce a muscle group and prevent or correct deformity. Medication may help reduce tension and limit other problems that involve nerve damage. Bio-engineering technology is creating many new devices to increase the mobility of persons with cerebral palsy and improve their ability to communicate.

Where Can Help Be Obtained?

The family doctor, public health nurse or clinic is usually familiar with the resources a community has for its residents who have disabilities. In many cities, and in most states, United Cerebral Palsy affiliates offer a wide range of services and facilities for the child and adult with cerebral palsy and similar service needs.

What Help Is Available?

UCP community services aim to meet the life-long needs of those with cerebral palsy. Programs of detection, treatment, care, education and psychological counseling are offered. Developmental centers focus on habilitating children with cerebral palsy. Parents are helped through counseling and instruction. Teenagers and adults may obtain job training, guidance and work experience that can lead to competitive employment.

Recreational opportunities are provided through camps, hobby groups and sports programs. For older persons, there may be residential facilities for independent living. Respite care programs relieve parents of the constant care required by a disabled family member. Home services are also available.

How Widespread Is Cerebral Palsy?

Some 700,000 persons in the United States are affected by cerebral palsy. About one-third are teenagers and young adults. Each year an estimated 3,000 babies are born with cerebral palsy or acquire it early in life. It is the most widespread lifetime disability in the nation.

More Facts About Cerebral Palsy

Is Research Helping?

Yes, definitely. United Cerebral Palsy's Research and Educational Foundation supports extensive research which has helped to develop the following, among other ways of preventing and managing cerebral palsy:

- Vaccines against viral infections, such as rubella or German measles, that can cause fetal injury if contracted by pregnant women.
- Safe and effective treatment for jaundice of the newborn, a factor closely associated with cerebral palsy.
- Measures to counteract the toxic effects on pregnant women of lead and other heavy metals in the atmosphere.
- Improved techniques for caring for premature babies that reduce the degree of

disability these babies are particularly susceptible to.

- Bio feedback therapy to train alternate nerve circuits to stimulate muscle function.
- Improved methods of determining in advance the likely success of surgery for orthopedic deformities.
- New and improved medications to alleviate physical symptoms of cerebral palsy.
- Wider use of communications devices for persons with speech and hearing difficulties.

However, much remains to be learned before cerebral palsy can be brought under control, and research is the key. UCP expends increasing amounts on research each year and also works to increase support for research from the federal government and other funding sources.

What Is United Cerebral Palsy?

United Cerebral Palsy is the only nationwide voluntary organization targeting its services on the specific and multiple needs of persons with cerebral palsy and their families. Its facilities are available also to other disabled persons. UCP's more than 180 state and local affiliates provide a wide variety of community services, take an advocacy role on behalf of persons with cerebral palsy and other disabilities, support research and the training of professional and scientific manpower, and conduct programs to educate the public about cerebral palsy. UCP is supported by contributions from the public, by government and other grants, and by bequests and legacies.

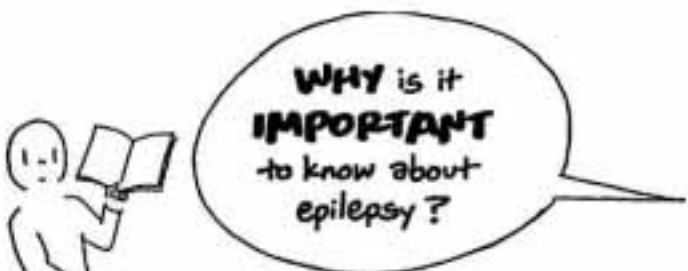
More information may be obtained from the United Cerebral Palsy affiliate in your area or by writing directly to UCP national headquarters.



**UNITED CEREBRAL PALSY
ASSOCIATIONS, INC.**

7 PENN PLAZA, SUITE 804, NEW YORK, N.Y. 10001

Facts About Epilepsy



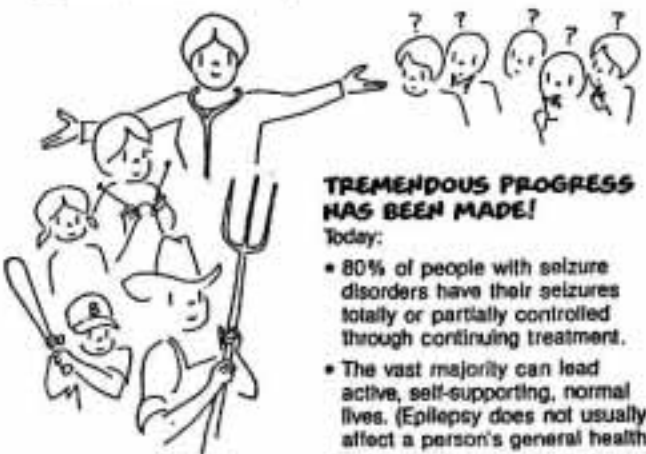
Because it's widespread and widely misunderstood.

EPILEPSY:

- affects more than 2 MILLION AMERICANS.
- can affect ANYONE.

IGNORANCE AND MYTHS

about epilepsy often cause more problems for a person with epilepsy than the condition itself.

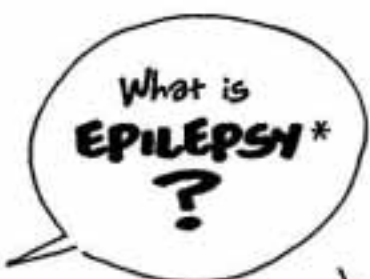


TREMENDOUS PROGRESS HAS BEEN MADE!

Today:

- 80% of people with seizure disorders have their seizures totally or partially controlled through continuing treatment.
- The vast majority can lead active, self-supporting, normal lives. (Epilepsy does not usually affect a person's general health.)

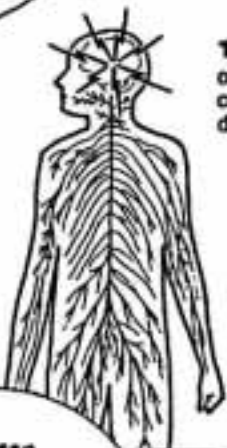
This booklet is not a substitute for an informed discussion between a patient and his or her physician of the procedures or medications described in this booklet.



It's a DISORDER OF THE CENTRAL NERVOUS SYSTEM.

BRAIN CELLS

(neurons) create abnormal electrical discharges that cause seizures – the temporary loss of awareness and/or control over certain body functions.



THE MANY TYPES

of epilepsy are often called seizure disorders.

SEIZURES

- may include:
- muscle spasms
 - mental confusion
 - a loss of consciousness
 - uncontrolled or aimless body movements.



EPILEPSY IS NOT:

- a disease
- contagious
- a mental illness
- a sign of low intelligence.

* The word "epilepsy" comes from the Greek word for "seizure."



A SCRYMPHOGRAPHIC BOOKLET by CHARVING L. WITTE CO., INC., South Duxbury, MA 01978 U.S.A.
© 1978 All rights reserved. Lithographed in U.S.A. 1988 Edition 11000017-00
To order: phone 800-625-7733 and request booklet number 11026.

More Facts About Epilepsy



Anyone can develop recurring seizures at any time.

SOME PATTERNS

BIRTH TO AGE 5

20% of all epilepsies show up in these years. Major causes are problems in pregnancy, birth defects, injuries, infections, fever.



AGES 5 TO 25

30% of cases become evident at this time. Many are triggered by accidents and illnesses.



AGES 25 AND UP

50% of epilepsies appear in middle and late adulthood. Major causes are head injuries, tumors and circulatory problems.

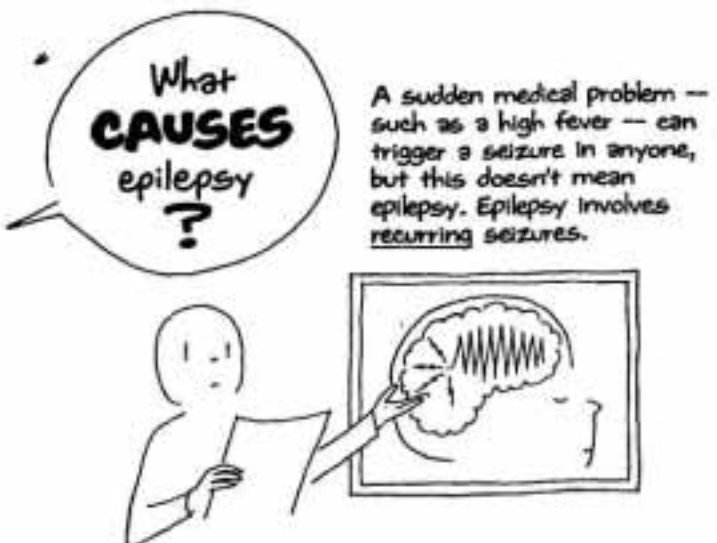


And--

MALES are slightly more likely to have epilepsy than females — perhaps because they're more likely to have head injuries in sports and work.



HEREDITY usually is not a direct factor in epilepsy. But some kinds of brain wave patterns associated with seizures do tend to run in families.



A sudden medical problem — such as a high fever — can trigger a seizure in anyone, but this doesn't mean epilepsy. Epilepsy involves recurring seizures.

Scientists know **HOW** these seizures occur, but they don't know **WHY**. We do know that recurring seizures can be related to:

DAMAGE to the central nervous system before, during or just after birth.



DEFECTS in the brain, present at birth.



HEAD INJURIES that can occur at any age.



POISONS — including lead, alcohol.



DISEASES such as measles, encephalitis.



DISORDERS of the circulatory system.



TUMORS — usually in the brain.



POOR NUTRITION or disturbances in metabolism.



...and there are many cases where no cause can be identified. (These are called "idiopathic.")

More Facts About Epilepsy

ABOUT EPILEPTIC SEIZURES



"GENERALIZED" SEIZURES

begin with a discharge of neurons throughout the brain. They include:

TONIC-CLONIC SEIZURES

- Sometimes called "grand mal."
- May occur at any age.
- Cause loss of consciousness and stiffening of body, followed by violent jerking of limbs and irregular breathing.
- Usually last 1 to 2 minutes.
- May occur often (once a day) or seldom (once every few years).
- Not dangerous unless continuous (very rare). (See pages 8-9.)



ABSENCE SEIZURES

- Sometimes called "petit mal."
- Most common in children ages 6 to 14.
- Cause "blank spells" — a loss of awareness, staring, blinking and slight twitching.
- Attacks last only a few seconds.
- May occur dozens or even hundreds of times a day.
- Hard to recognize; may be mistaken for daydreaming or inattentiveness.



"PARTIAL" SEIZURES

begin with a discharge of neurons in just one part of the brain. They include:

SIMPLE PARTIAL SEIZURES

- May occur at any age.
- May be limited to uncontrolled body movements.
- May involve brief changes in how things look, sound, taste or feel.
- Do not usually affect consciousness.



COMPLEX PARTIAL SEIZURES

- May occur at any age.
- Cause confusion or a loss of awareness, and aimless movements (picking at one's clothes, lip-smacking, etc.).
- Confusion after a seizure may be prolonged. This is occasionally mistaken for alcohol or drug intoxication.



EPILEPTIC SEIZURES VARY

- Seizures may be frequent or rare.
- They may last a second or several minutes.
- They may be severe or mild.
- A person can have more than one type of seizure.
- The pattern of seizures may change with time.

MYOCLONIC SEIZURES

Abnormal electrical activity throughout the brain causes brief muscle jerks strong enough to throw a person to the ground.



INFANTILE SPASMS

Some babies have sudden, jerking seizures during which they bend at the waist or seem to reach up for support.



There are many
**LESS COMMON
TYPES**

For example:

More Facts About Epilepsy

TONIC-CLONIC SEIZURES

are the most common type of major seizure — and the most noticeable. They're also the most likely to respond to treatment.

COMMON STAGES:

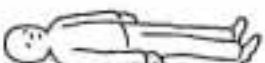
1 AURA

A partial seizure can spread to become a generalized tonic-clonic seizure. Some people experience odd sensations, such as unpleasant odors or spots before their eyes. This warning feeling is called an "aura."



2 TONIC PHASE

The person loses consciousness, falls down and becomes rigid. Breathing becomes irregular (In some cases it may even stop briefly).



3 CLONIC PHASE

Jerking of muscles, clenching of teeth and general convulsions occur for one to several minutes. (Some people experience only one type of spasm, either tonic or clonic.)



4 RECOVERY STAGE

Muscle movements slow, then stop. The person regains consciousness. He or she may be tired, confused or have a headache. Rest or sleep may be needed.



WHAT TO DO

If someone has a tonic-clonic seizure.

STAY CALM

— don't try to restrain or revive the person. If the person is seated when the seizure starts, help ease him or her to the floor.



REMOVE HAZARDS

such as hard, hot or sharp objects that could cause injury if the person falls or knocks against them.



DON'T MOVE THE PERSON

unless the area is clearly dangerous, such as a busy street. Loosen tight clothing and remove glasses.



PROTECT AIRWAYS

by gently turning the person on one side so any fluid in the mouth can drain safely. Never try to force the mouth open or put anything into it.



DON'T CALL A PHYSICIAN OR AMBULANCE, UNLESS:

- the person is not known to have epilepsy
- the person's identification shows he or she has diabetes
- the seizure is prolonged
- one seizure follows another
- the person is pregnant, ill or injured.

WHEN THE SEIZURE ENDS, let the person rest or sleep if he or she wishes. Be calm and reassuring because the person may feel embarrassed or disoriented after an attack.



QUESTION #2:



How do we define the person's needs?

- ----- ROLE EXPECTATIONS -----

A person's behavior tends to be profoundly affected by the role expectations that are placed upon him or her -- generally people play roles that are assigned...

This permits those who define (control) to make self-fulfilling prophecies predicting that someone cast into a role will emit behavior consistent with the role...

Then this behavior is interpreted as the person's natural behavior.

-
- *FOCUS ON DEFICIENCY*
 - *ASSESSMENTS, TESTS AND DIAGNOSIS*
 - *BAD REPUTATIONS AND « CHALLENGING BEHAVIOR*

How we define needs...

DEVELOPMENTAL DISABILITIES

10.22.05.07

(c) Individual's plan of habilitation as required by Health-General Article, §7-1006, Annotated Code of Maryland, is adequate and suitable; and

(d) State residential center has complied with and executed the individual's plan of habilitation in accordance with all applicable regulations, and standards that the Secretary of Health and Mental Hygiene adopts.

C. Before the annual comprehensive program review, evaluations,

C. Before the annual comprehensive program review, evaluations, relevant to the client's needs, shall have been completed.

D. The evaluations shall identify:

(1) Additional disabilities or problems that may have arisen since the initial evaluation;

(2) The individual's specific strengths;

(3) The individual's specific needs; and

(4) The individual's needs for services, without regard to the actual availability of the services needed.

(5) Needs, regardless of the availability of services; and

(6) Preferences and the consideration given these.

C. Time Frame.

(1) The initial IHP shall be completed within 21 calendar days of an individual's State residential center admission or 30 calendar days of a community program admission. The day of admission shall be counted as the first day of these days.

(2) An IHP developed by another agency from which the client has transferred shall be reviewed by the interdisciplinary team within 21 or 30 calendar days of the transfer, as applicable, to determine its relevancy to the current needs of the individual. The IHP shall be updated if necessary.

Sample Page from ICAP

D. ADAPTIVE BEHAVIOR				ICAP 8/85 Page 5
<p>* Rate how well the client presently performs each task <u>completely and without</u> help or supervision.</p> <p>* Mark the space to the left of each item that best describes the client's performance.</p> <p>* Tasks that are now too easy for the client should be given a rating of 3.</p> <p>* If you have not had the opportunity to observe performance on a task or the client does not have the opportunity to perform the task, estimate how well the client <u>could</u> do the task on his or her own without further training.</p> <p>* Consult the <u>ICAP Manual</u> for further instruction.</p>				
1. MOTOR SKILLS				
DOES (or could do) TASK COMPLETELY WITHOUT HELP OR SUPERVISION:				
0	1	2	3	
NEVER OR RARELY Even if asked	DOES, BUT NOT WELL -OR- DOES 1/4 OF THE TIME May need to be asked	DOES FAIRLY WELL -OR- DOES 3/4 OF THE TIME May need to be asked	DOES VERY WELL ALWAYS OR ALMOST ALWAYS Without being asked	
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1. Picks up small objects with hand.
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2. Transfers small objects from one hand to the other hand.
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	3. Sits alone for thirty seconds with head and back held straight and steady (without support).
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	4. Stands for at least five seconds by holding on to furniture or other objects.
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	5. Pulls self into a standing position.
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	6. Puts small objects into containers and takes them out again.
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	7. Stands alone and walks for at least six feet.
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	8. Scribbles or marks with a pencil or crayon on a sheet of paper.
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	9. Removes wrappings from small objects such as gum or candy.
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	10. Turns knob and opens a door.
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	11. Walks up and down stairs by alternating feet from step to step. (May hold handrail.)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	12. Climbs a six-foot ladder (for example, a step ladder or a slide).
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	13. Cuts with scissors along a thick, straight line.
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	14. Prints first name, copying from an example.
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	15. Picks up and carries a full bag of groceries at least twenty feet and sets it down.

SAMPLE GOALS:

(Found in actual files)



DEVELOPMENTAL AREA

GOAL

- **(Eating / Drinking)**

Consumer will independently feed self without spillage on 10 trials.

- **(Toileting)**

Consumer will eliminate in the toilet 4/4 times per day for 8 trials.

- **(Dressing /
Undressing)**

Consumer will complete 100% of the task analysis steps for dressing self on 8 trials.

- **(Meal Preparation)**

Consumer will independently prepare a simple dish consisting of toast, cereal, and juice for 5 consecutive trials.

- **(Menstruation)**

Consumer will chart on the calendar when the next menstrual cycle will occur on 4 trials.

- **(Ambulation)**

Consumer will walker ambulate 25 feet every day for 4 consecutive trials.

- **(Hair Care)**

Consumer will independently complete 10/10 steps for washing on 3 consecutive trials.

- **(Grooming)**

Consumer will follow 5/5 task analysis steps for combing hair on 10 successful trials.

- **(Sensory
Development)**

Consumer will grasp and hold an eating utensil for 10 seconds on 5 consecutive trials.

Stereotyped Roles

■ — LIST	COMMENTS
-----	1

- *SICK*
- *SUB-HUMAN*
- *HOLY-INNOCENT*
- *ETERNAL CHILD*
- *SOCIAL MENACE*
- *OBJECT OF DREAD*
- *OBJECT OF RIDICULE*
- *OBJECT OF PITY/CHARITY*
- *A COMMODITY*

Why is this important?

QUESTION #3:



What is Our Relationship
with Community?

- *Community: A Place of Fear, Ignorance and Discrimination*
- *Waiting for the Community to Get Ready -- Accept Us*

Notes:

We view community as hostile
and ignorant...

Not in my back yard

Many oppose use of house for mental patients

By Patrick Ercolano

In a tense 90-minute meeting last night, about 100 Rodgers Forge residents voiced their opinions of a plan by the Sheppard Pratt Health System to house mentally ill out-patients in the community just south of Towson.

Sheppard Pratt officials called the meeting, held in the auditorium of Rodgers Forge Elementary School, so residents of the 1,777-house community could learn more about the proposal to place three out-patients in a three-bedroom detached home at 7112 York Road this spring.

Carl Francioli, who lives next door to the planned "alternative living unit," said, "I have nothing against the idea or against the types of people who will live there, but I have an investment to protect. My wife and I have every penny we own invested in our home, and you can't tell me this program isn't going to hurt my property value."

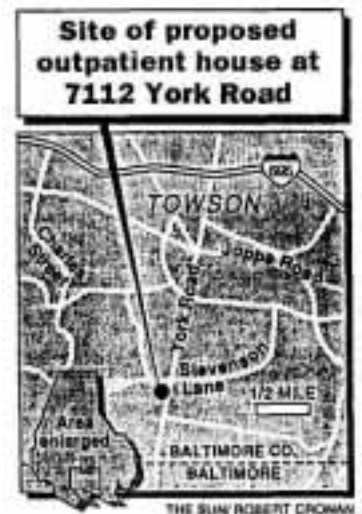
If the applause following similar statements was any indication, more than half the crowd opposed the plan. But some residents offered their support of the proposal, pointing out that

Rodgers Forge already has two ALUs virtually unknown to the community because they have been so free of problems.

Sheppard Pratt purchased the house last week for \$132,000, or \$12,000 below the list price. The patients, who have yet to be selected, will have been treated for an average of 30 days at the hospital for illnesses such as severe depression, eating disorders and schizophrenia.

The first three patients are expected to move in around April 1 and will reside at the house for about a year. They will be of the same sex and live without supervision, but they will be contacted daily by telephone and in person by hospital workers. The patients also will be able to phone Sheppard Pratt for assistance 24 hours a day.

They will be required to spend 20 hours each week in a job, a volunteer activity or a treatment program. The costs of the program will be paid by the patients themselves or their health insurers.



The Evening Sun, Thursday, February 6, 1992

<u>POSITIVE</u>	<u>NEGATIVE</u>
...that value, enhance and build high self-esteem and respect	...that devalue, diminish and contribute to low self-esteem and disrespect

- 1.
- 2.
- 3.
- 4.

QUESTION #4:



Who is in Control?

- *Top Down — Regulation, Bureaucracy and C. Y.A.*
- *Documentation and Compliance with Standards: The Process Game*
- *Daily Activities, Routines and Rhythms*
- *Choices and Decision-Making*
- *Behavior Management*

Notes:

CONTROL!!!



LEARNED HELPLESSNESS . . .

. . . results from the belief that nothing that one does makes any difference . . .

Persons experiencing learned helplessness characteristically see no relationship between actions and outcomes . . .

. . . they frequently manifest passivity, negative expectations, and tendencies to self-deprecation .

Seligman, M. (1975)

Helplessness: on depression, development and death.

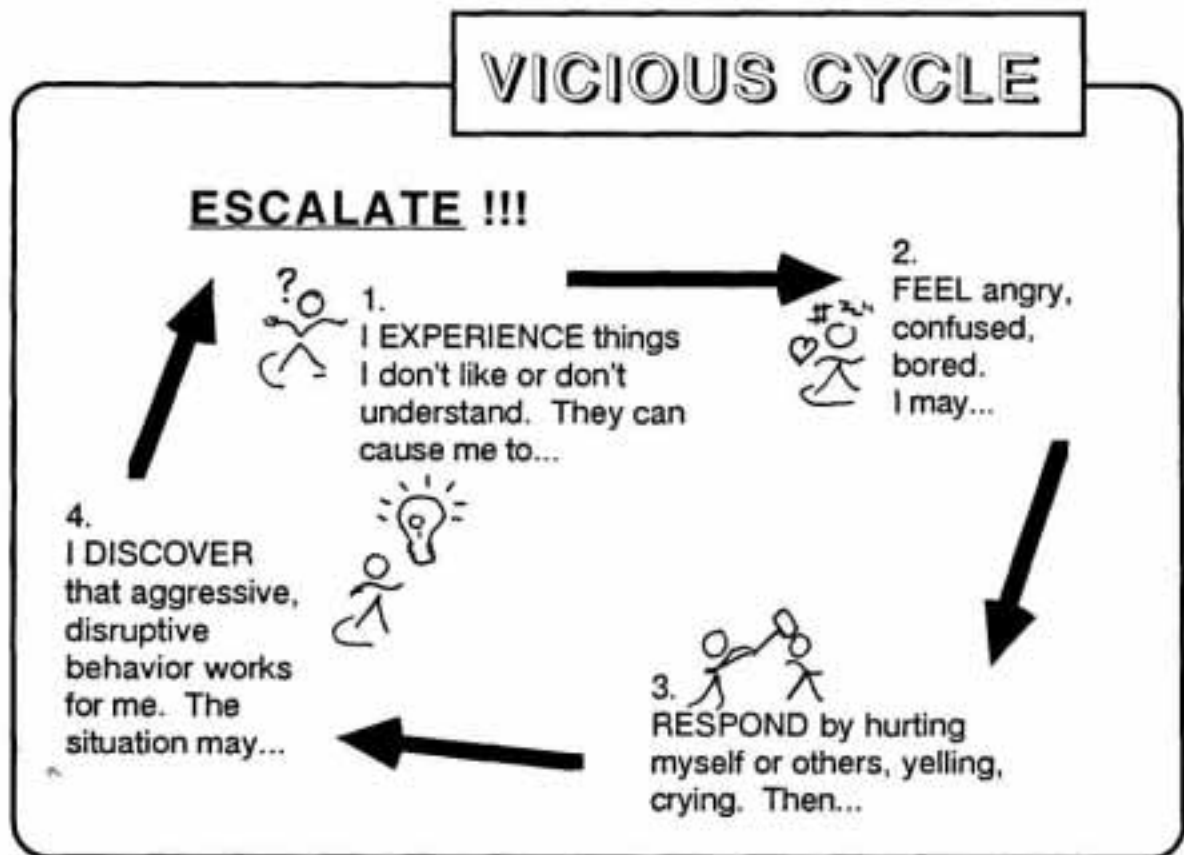
**Source: TASH JOURNAL
1989**

CHOICES: Rights/Decision-Making/Choice

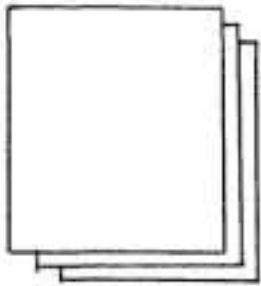
<p>What Choices Do STAFF (OR OTHERS) Make for the Person?</p>	<p>What Choices Does the PERSON Make for SELF?</p>
---	--

What are your strategies to increase the Person's Choice and Decision-Making?

- 1.
- 2.
- 3.
- 4.
- 5.
- 6.



QUESTION #5:



How Do We Define
Our Role?

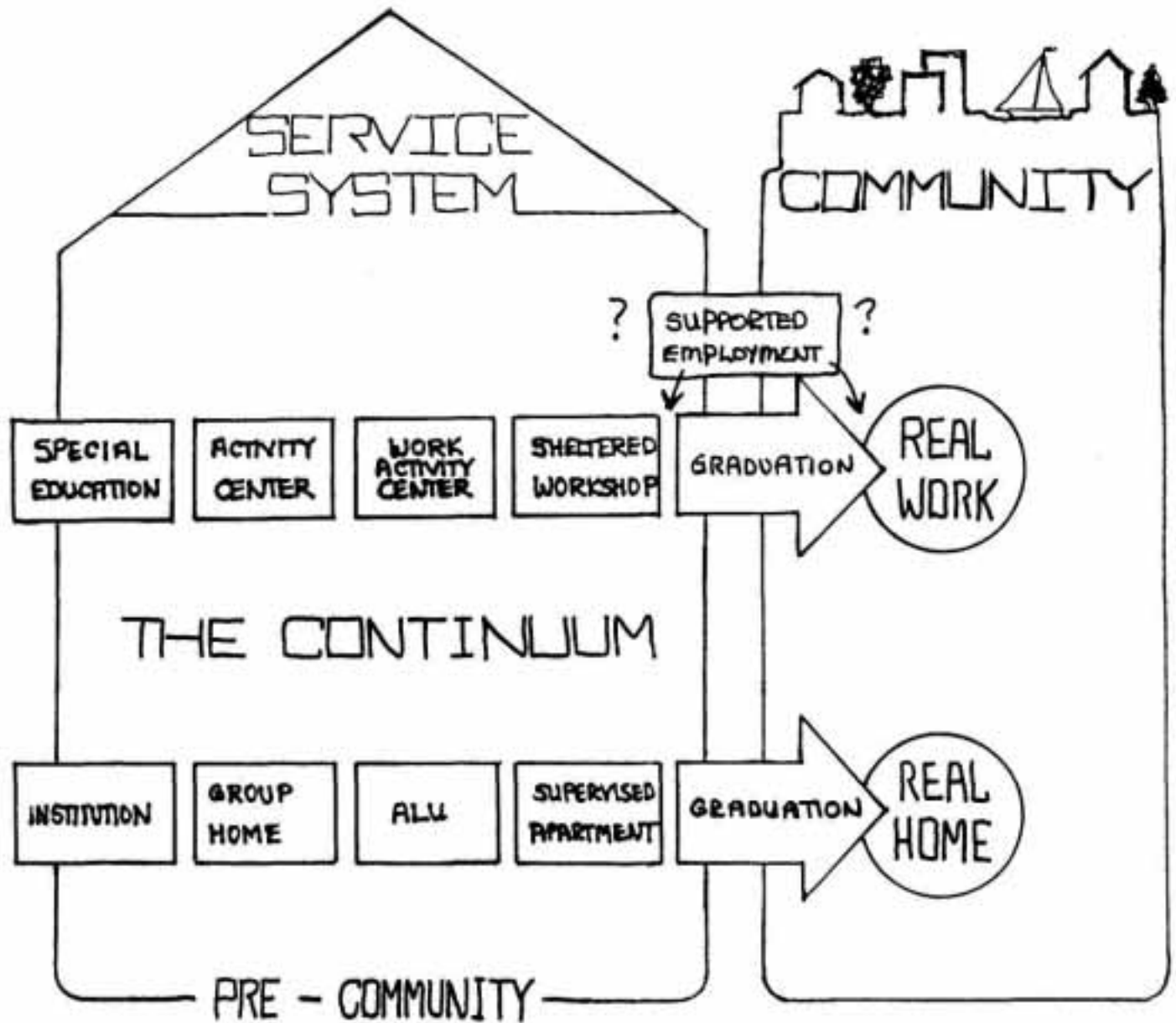
*An Analysis of Current Models and
Program Practices*

- *Continuum Model*
- *Pre-Community, Getting Ready*
- *'Fix the Disability' Approach*

*Congregation, Segregation and Group
Mentality*

*What are the Messages that We Send to
the Public?*

The Service System Continuum



The "Readiness" Model

Despite the promise and progress of the last decade, thousands of adolescents and young adults with disabilities are trapped by the conventional wisdom of curriculum design in special education and adult human services. They are confined, not by physical barriers, but by widely shared assumptions about what they should learn and the order in which it should be presented. In effect, individuals with moderate and severe disabilities are trapped by the readiness model.

Barbara Wilcox, 1987

MODELS and LANGUAGE

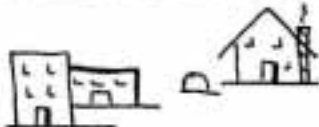

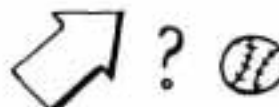

EDUCATIONAL	CLINICAL	COMMUNITY*
<ul style="list-style-type: none">• School• Classes• Class Period• Teaching (Teachers)• Team Teaching• Students• Approach• Expectations• Curriculum• Enrollment• Graduation• School Environ.• Term• Learning• IEP• Records / Files	<ul style="list-style-type: none">• Day Treatment• Groups• Session• Therapy (Therapist)• Inter-Discpl. Team• Clients/Patients• Treatment Modality• Prognosis• Prescription• Admission• Discharge• Milieu• Length of Stay• Therapeutic• IHP/ITP• Records / Files	<ul style="list-style-type: none">• Home-Work-Soc/Leis.• Relationships• Stages / Passages• Experiences• Circle of Friends• Citizen (Neigh., Mem.)• Support Circle• Dreams• Lifestyle• Birth• Death• Community Places• Lifetime• Sharing-Contributing• PFP• Stories

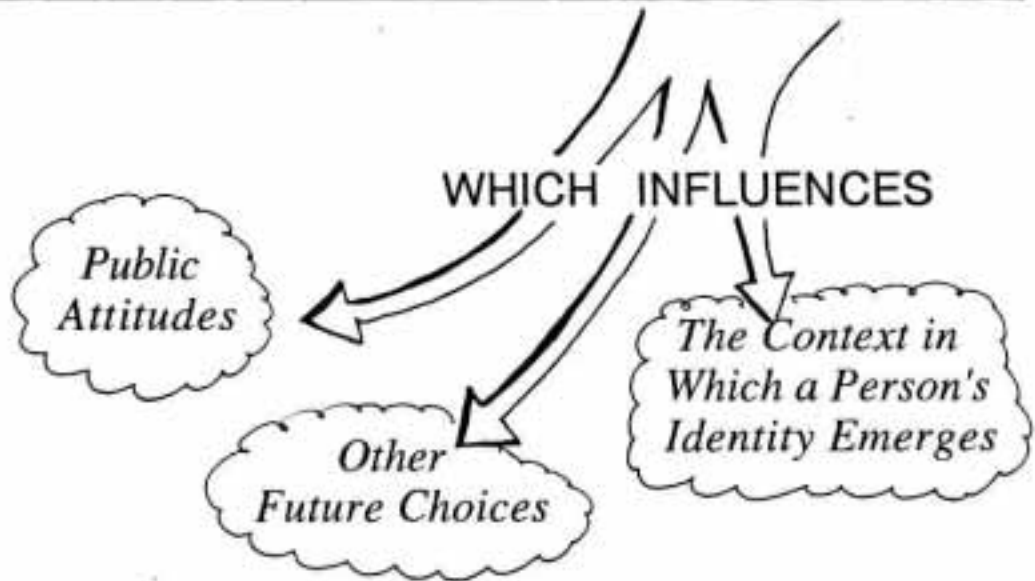
**NOTE: Community is not a model to be implemented - but is shown here for comparison to existing models.*

Over time...

WE INFLUENCE



• WHERE		<i>Settings</i>
• WITH WHOM		<i>Groupings</i>
• WHAT		<i>Activities</i>
• WHO		<i>Languages & Images</i>



QUESTION #6:



What is Our Vision for the Future?

- *Vicious Circles and Self-Fulfilling Prophecy*
- *Living Down to Our Expectations*
- *More of the Same: The 'Readiness Trap'*

Notes:

PART TWO:

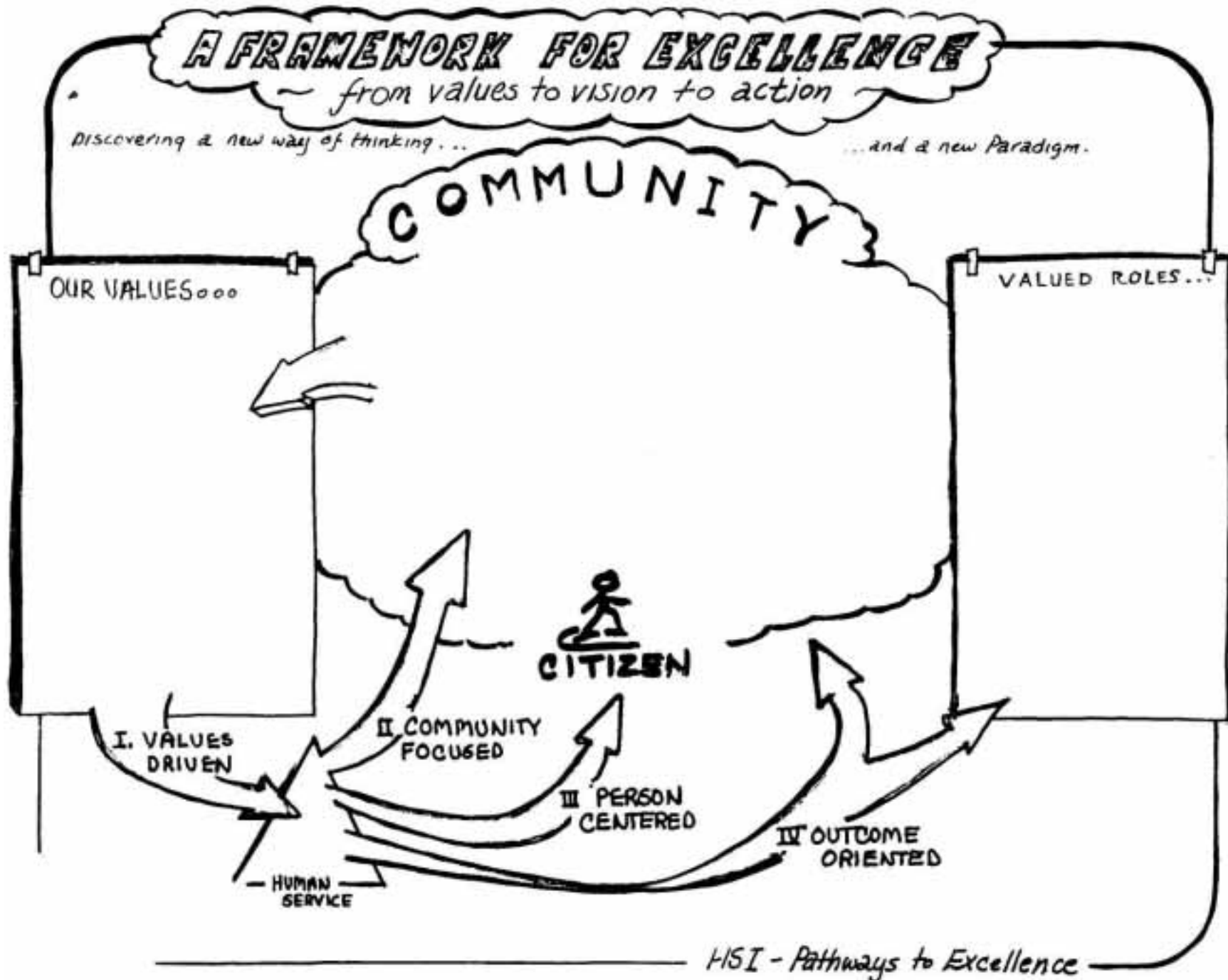
Framework for Excellence

*A New Way of Thinking ... Planning
and Acting!*

The Pathway to Citizenship

Guiding Principles for Quality Human Services:

- VALUES DRIVEN vs. REGULATION DRIVEN
- COMMUNITY FOCUSED vs. PROGRAM FOCUSED
- PERSON CENTERED vs. DEFICIENCY CENTERED
- OUTCOME ORIENTED vs. PROCESS ORIENTED



GUIDING PRINCIPLE #1:

VALUES DRIVEN

- Reaffirming Values:
The Foundation for Our Beliefs
About People and Community
- Normalization/Social Role
Valorization

Values Worksheet

COMMUNITY VALUES: What are our Core Beliefs?

NOTES:

Why are Values Important?

For Me?

For the Program?

For People with Disabilities?

Things to Remember...

IDEOLOGY ...a set of beliefs

The PRINCIPLE OF NORMALIZATION means...

... making available ... patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life of society.

Nirje, 1970

... the use of culturally valued means in order to establish and/or maintain personal behaviors, experiences and characteristics that are culturally valued or normative.

Wolfensberger, 1977

SOCIAL ROLE VALORIZATION means...

... that will establish, enable and support people to have valued social roles in the community.

Social Role Valorization
Wolfensberger, 1983

Understanding the Shift from...

NORMALIZATION PRINCIPLE to SOCIAL ROLE VALORIZATION (SRV)

- **The term "normalization," largely misunderstood, results in creation of a life of client hood.**
- **"CLIENT" is a devalued social role.**
- **Being devalued brings with it three consequences:**
 - 1. Devalued people are treated badly.*
 - 2. Bad treatment takes the forms of the devalued societal role...*
 - Retarded children, viewed as slow animals, might be placed in the playgroup called "the turtles."*
 - People perceived as menaces might be served in settings that look like fortresses or are remote from communities.*
 - 3. How people are treated by others strongly determines how they behave.*
- **Helping to cast people in VALUED social roles.**

ANALYSIS of SOCIAL ROLES...

The Social Role of CLIENT:

--

The Social Role of _____ :

--

Normalization/Social Role Valorization EXERCISE

Assign a "1" to those practices/accomplishments that a substantial number of typical community members would value negatively, a "3" to those practices which would be regarded as neutral, and a "5" to practices/accomplishments typical community members would value highly.

- ___ 1. Living in a locked institution unit.
- ___ 2. Living in one's own apartment with a roommate.
- ___ 3. Being an employer.
- ___ 4. Being unemployed and supported by social service benefits.
- ___ 5. Spending the day doing arts and crafts without pay.
- ___ 6. Going to a class in a public school building.
- ___ 7. Going to a class that meets in a "special school" for people who are mentally retarded.
- ___ 8. Being dirty and unkempt and wearing dirty, sloppy clothes.
- ___ 9. Being clean and neatly dressed.
- ___ 10. Drooling continuously and slurring speech.
- ___ 11. Using a wheelchair to assist mobility.
- ___ 12. Winning a competitive athletic event.
- ___ 13. Being a church leader.
- ___ 14. Being "severely mentally retarded."
- ___ 15. Having good friends who will help you when you need it.
- ___ 16. Helping a friend.

COMMENT: You may find it a bit uncomfortable to describe the response of typical community members to handicapping conditions. For many people being severely retarded is, itself, a negatively valued condition. Having difficulty controlling your mouth, tongue and facial muscles is negatively valued. (Many people do devalue people with major mobility problems.) These are social facts of handicapped people's lives.

GUIDING PRINCIPLE #2:

COMMUNITY FOCUSED

- Community Presence:
 - Places...Where to Go
 - Activities...What to Do
- Community Participation:
 - Relationships
 - Associations

Community Worksheet

COMMUNITY IS...

NOTES:

Why is Our Being in Community Important?

For Me?

For People with Disabilities?

For the Community Itself?

Things to Remember...

GUIDING PRINCIPLE #3:

PERSON CENTERED

- Citizenship:
Life, Liberty and the Pursuit
Happiness
- Getting to Know the Person
...One Person at a Time
- Dignity and Respect
- Redefining Needs-Focus on
Capacities, Gifts and Talents
- Constructive Response to
Challenging Behaviors

Person Centered Worksheet

PERSON CENTERED MEANS...

NOTES:

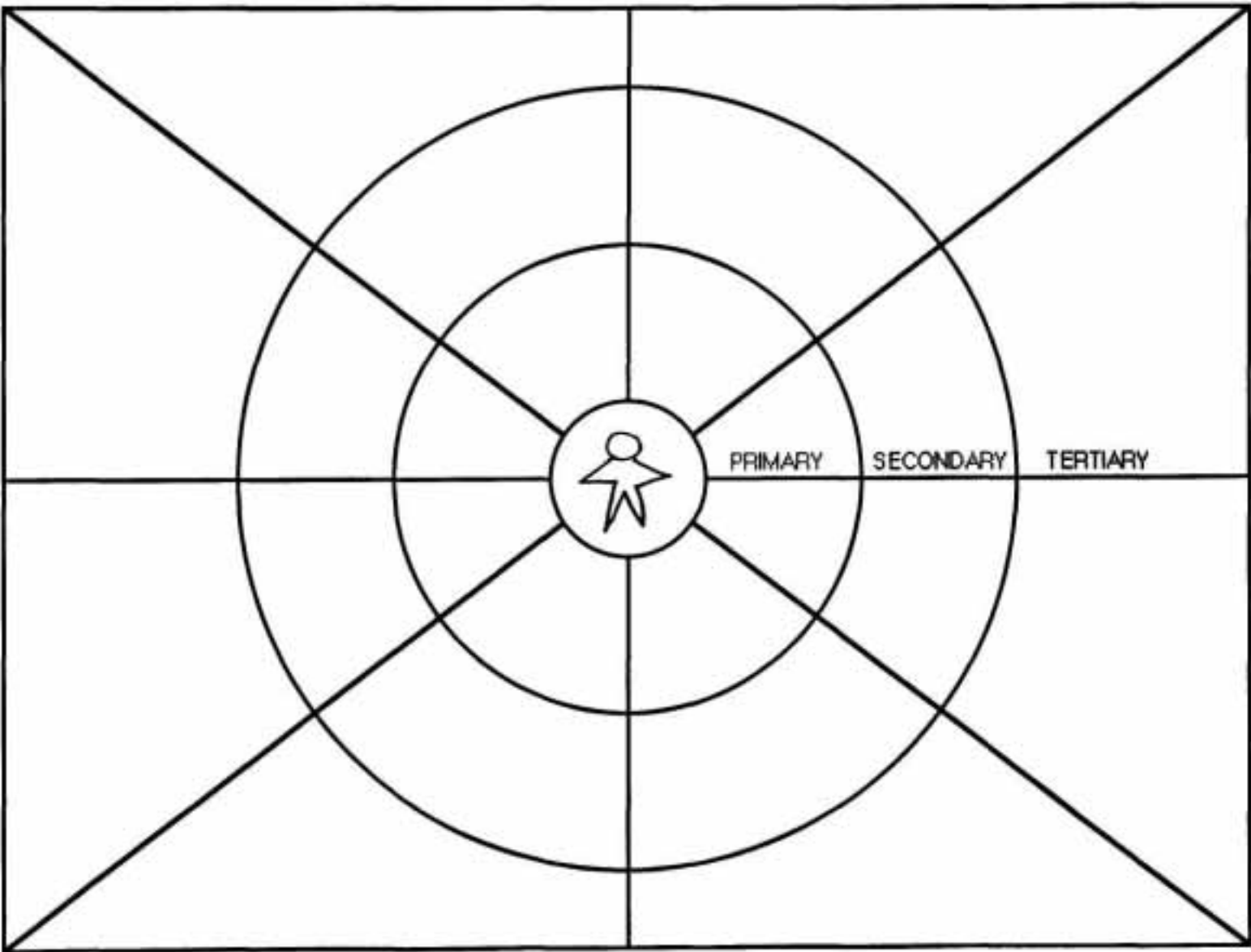
Why is Being Person Centered So Important?

For Me?

For People with Disabilities?

Things to Remember...

Relationship Map



RIGHTS vs. PRIVILEGES

RIGHTS

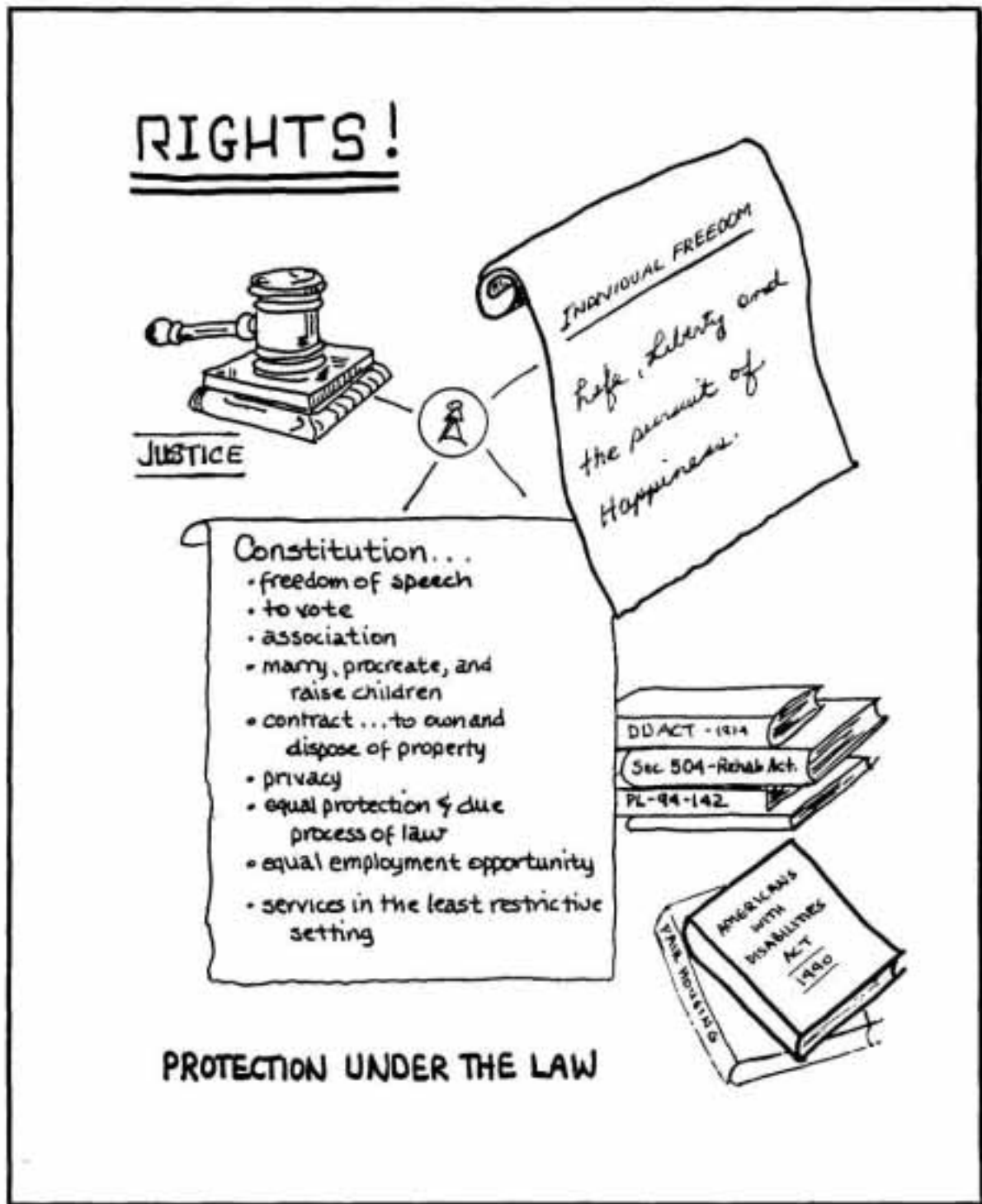
Something to which one has a just claim
or is entitled to.

Something one may properly claim as due.

PRIVILEGE

A Right or immunity granted
as a peculiar benefit, advantage
or favor.

RIGHTS!



on CHOICE and SELF DETERMINATION

Each choice we make is an expression of our personal autonomy.—our freedom to define who we are and what we value.

The opportunity to make choices provides us with power to determine, to a great extent, what happens to us on a moment-by-moment basis, as well as over the span of our lives.

To have the power to make choices taken away, for many of us, would be devastating if not unbearable!

D. Guess, H.A. Benson, E. Siegel-Causey
Concepts Related to Choice-Making
and Autonomy Among Persons with
Severe Disabilities. TASH. 1985

MAKING CHOICES



STRATEGIES for HONORING CHOICES

STRATEGIES FOR HONORING PERSONS CHOICE

- Listen to the person
- Promote & explore options
- Clear role
- Build relationships ~ allies
- Make commitments
- Respect Person
- Willingness to bend rules & take risks

LEAST RESTRICTIVE ENVIRONMENT

"... the alternative that represents the least amount of intrusion in a persons life... and the least amount of deviation from natural patterns and typical conditions of the community."

Some Guiding Principles . . .

- "If it ain't broken - don't fix it!"
- "If it is broken - don't fix more than necessary!"
- First, do no harm:
- "Do unto others, as you would have them do unto you."

"... the least amount of service necessary that will enable maximum self-determination and functional citizenship."

More on...

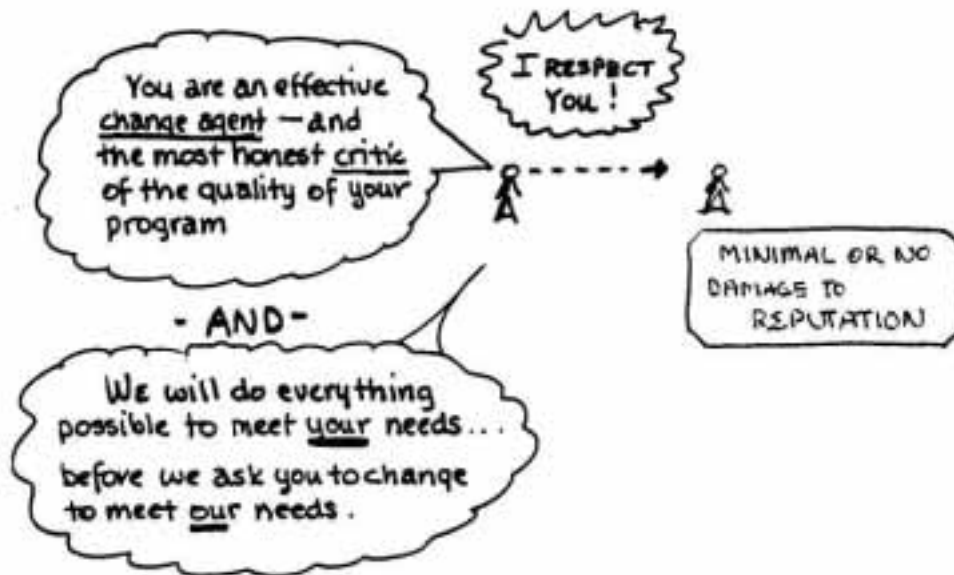
LEAST RESTRICTIVE ENVIRONMENT

Strive for —

... the supports that represent the least amount of intrusion in a person's life ... and the least degree of deviation from natural patterns and typical life style of everyday community life.

in other words...

the least amount of service necessary in the most natural and respectful way possible to enable maximum dignity, self-determination and citizenship.



To do this we must...

Get a real good sense of what is and has gone on in this person's life...

We need to look at and better understand person's life circumstances!

UNDERSTANDING BEHAVIOR CHALLENGES

BASIC ASSUMPTION:

*There are always reasons for why
people do what they do .*

*The first step in helping people
change their behavior ... is to
understand the causes for
their behavior .*

UNDERSTANDING CHALLENGING BEHAVIOR

PHYSICAL CAUSES for problem behavior :

- Do occur , but only rarely
 - when in doubt - check it out.
- Careful physical exams are very important for people with difficulty communicating how they feel.
- Inappropriate use of behavior controlling drugs can be a cause for challenging behavior.

Environmental causes :

our behavior is strongly influenced by our environment ... especially our learning experiences.

UNDERSTANDING CHALLENGING BEHAVIORS

THINGS TO REMEMBER :

- ❑ There are no Great and Desperate Cures.
- ❑ Environment is a major cause or contributing factor
- ❑ That challenging behavior has a strong communicative function.
- ❑ We must individualize our effort to create and maintain supports and services to the person
- ❑ The distinction between simply managing a persons behavior vs. supporting person to change .

GUIDING PRINCIPLE #4:

OUTCOME ORIENTED

- Valued Social Roles
- Lifestyle
- Personal Futures Planning

Outcome Oriented Worksheet

OUTCOME TERMS

PROCESS TERMS

NOTES:

Why is Being Outcome Oriented Important?

For me?

For People with Disabilities?

Things to Remember...

----- Critical Analysis Revisited

PART THREE:

Action for Empowerment

Discovering the Future

- The Five Essential Program Accomplishments
- Traditional "Individualized Habilitation Plans" and Person Centered Plan "Mapping"
- Going Back to Work

Five Essential Accomplishments of Human Services

The principle of normalization/social role valorization identifies five essential accomplishments which define effective services. Taken together, these accomplishments provide a focus for effort on behalf of individuals (individual habilitation planning), for organizational alignment (program planning, management, and evaluation), and systems development (regional planning, management, and evaluation).

COMMUNITY PRESENCE means creating conditions that provide as many opportunities as possible for individualized experience of a wide range of natural community settings. For many people who depend on human services, this includes support for movement from physical isolation and congregation with large groups of other people with identified handicaps to physical presence in the same neighborhoods, schools, work places, stores, recreation sites, and churches and synagogues as the rest of us. Program planners keep groupings small, avoid self-contained schedules and settings as much as possible, and disperse program settings throughout natural communities.

PROTECTION OF RIGHTS AND PROMOTION OF PERSONAL INTERESTS means creating conditions such that personal rights are protected and individuals are encouraged to understand their situation and the options they face and act in their own interest. Staff provide organized support for people to develop the ability to choose, to communicate interests and preferences both in everyday activities and in forums such as individual habilitation planning meetings, grievance procedures, planning hearings, and board meetings. When a person appears incapable of acting effectively in his/her own behalf, there are self-supported links to a citizen advocate, an attorney, or a guardian.

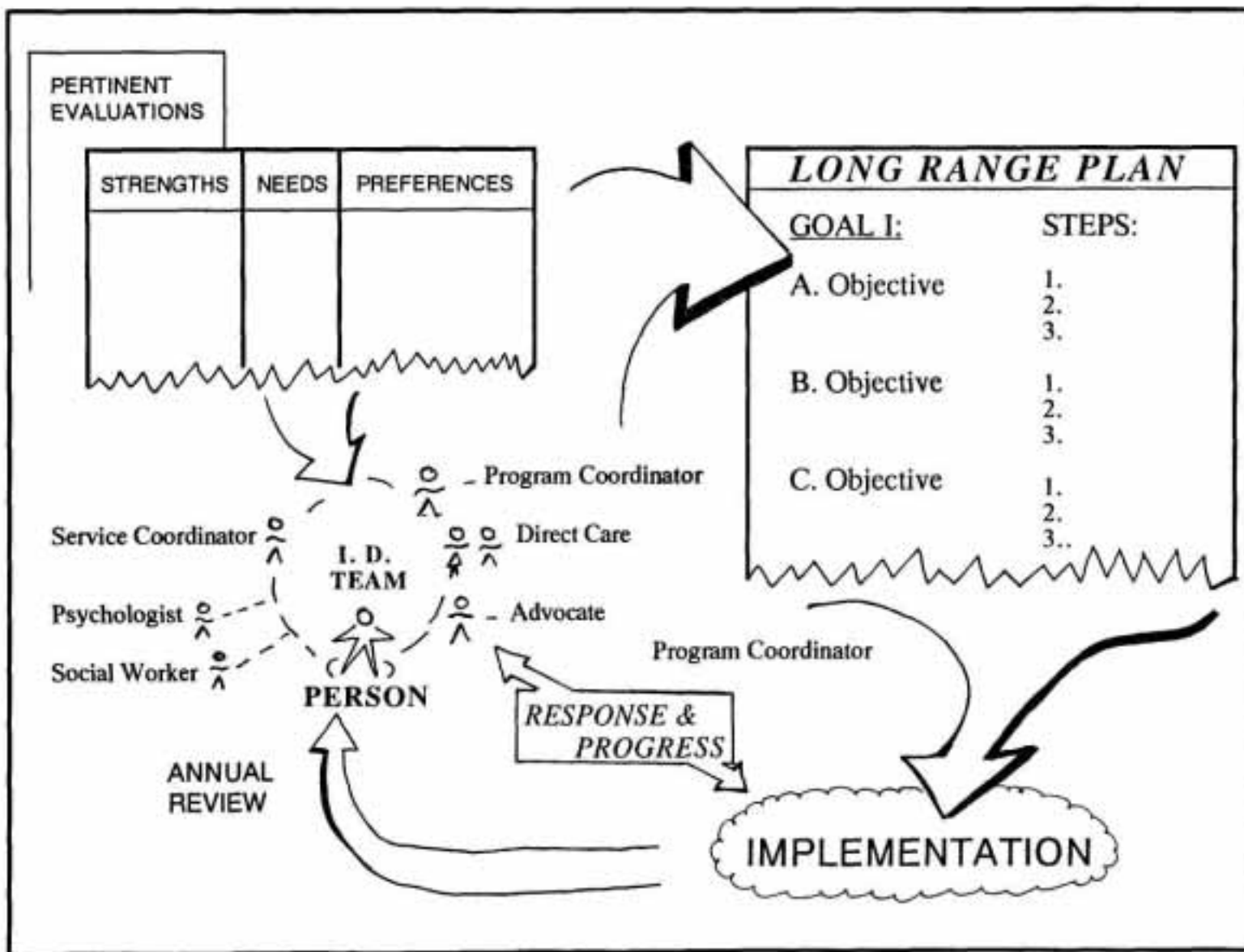
COMPETENCE DEVELOPMENT means building on individual skills, strengths, and interests to develop skills and attributes that are functional and meaningful in natural community environments and relationships. Skills and attributes are functional and meaningful if they significantly decrease a person's dependency or if they develop personal characteristics that other people need and want. Functionality and meaningfulness are defined in terms of relationships with known people in specific community settings.

STATUS IMPROVEMENT means developing and maintaining a positive reputation for people who use a service. Staff ensure that patterns of activity, language, and other symptoms actively promote the perception of people with handicaps as fully human, developing citizens. Individual service consumers are assisted to minimize the impact of personal characteristics that draw negative attention and reinforce negative stereotypes.

COMMUNITY PARTICIPATION means actively supporting people's natural relationships with their families, neighbors, and co-workers and, when necessary, widening each individual's network of personal relationships to include increasing numbers of people who are not also handicapped.

by John O'Brien

Overview of the IHP Process



-- Sample IHP Form -

* NAME: _____ PROGRAM COORDINATOR: _____

DATE OF PLAN: _____

GOAL: _____

	<u>OBJECTIVES</u>	<u>DATE</u>	<u>METHODS/STEPS</u>
--	--------------------------	--------------------	-----------------------------

A WELL WRITTEN GOAL WILL BE:

MEASURABLE-

I know it has been met!

OBSERVABLE -

I can see it!

REPLICABLE --

It could be done again!

As an uninvolved person...I should be able to:

- *Read it*
- *Understand it*
- *Implement it*

WRITING CLEAR GOALS: An Exercise

The CLEAREST WAY to write a goal is to describe what the person will be doing when the goal is achieved!

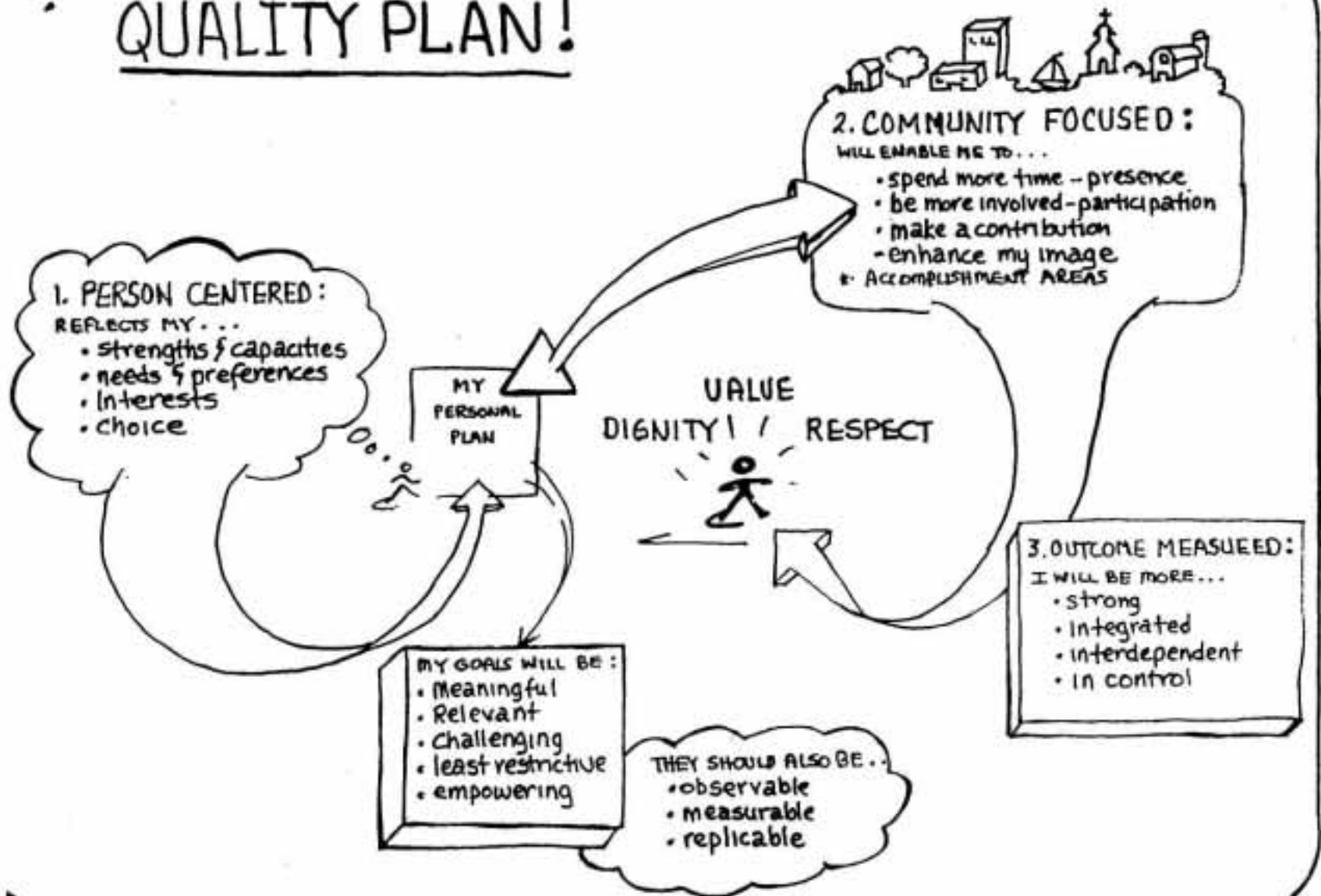
VAGUE GOALS

1. Socialize more
2. Control behavior
3. Improve eating manners
4. Improve personal hygiene
5. Become less dependent
6. Assume more responsibility

CLEAR GOALS

CRITERIA FOR A VALUES DRIVEN

QUALITY PLAN!



HSI

PATHWAYS TO EXCELLENCE on GOAL PLANNING

Assumptions...

- *Direct service staff are not in a position to fundamentally change the way goal planning is done where they work.*
- *Direct service staff care about the lives of the people who rely on them each day.*
- *Direct service staff will work hard on goals for people that are meaningful, relevant, and make a difference to the person.*
- *Direct service staff can have a significant impact on a person's life through a person's plan.*
- *The existing planning process — while flawed -- can be used as a tool to help make good things happen in peoples' lives.*

Therefore...

PATHWAYS will help staff to discover strategies to effectively use the existing planning process to make a qualitative difference in peoples' lives.

HSI POSITION on PERSONAL LIFESTYLE PLANS

All people, as citizens, have the right to self-determination. People should be supported to plan for and pursue a lifestyle of their choice including making major boundary decisions...

- Where to live...
- With whom to live...
- Where and when to work, or other ways to be in community...
- How to spend their leisure time...
- How to spend their money...
- Who to spend time with...and the nature of these relationships...

...as well as everyday lifestyle choices within these boundary decisions.

Each person is entitled to a personal plan as a tool to communicate their preferences and as a way to bring people together to help them to pursue their life goals.

PERSON CENTERED PLANNING

Why a personal plan
is a good idea...



1. Documents person's preferences, goals and what is important!
2. Provides a record...and hopefully some continuity over time.

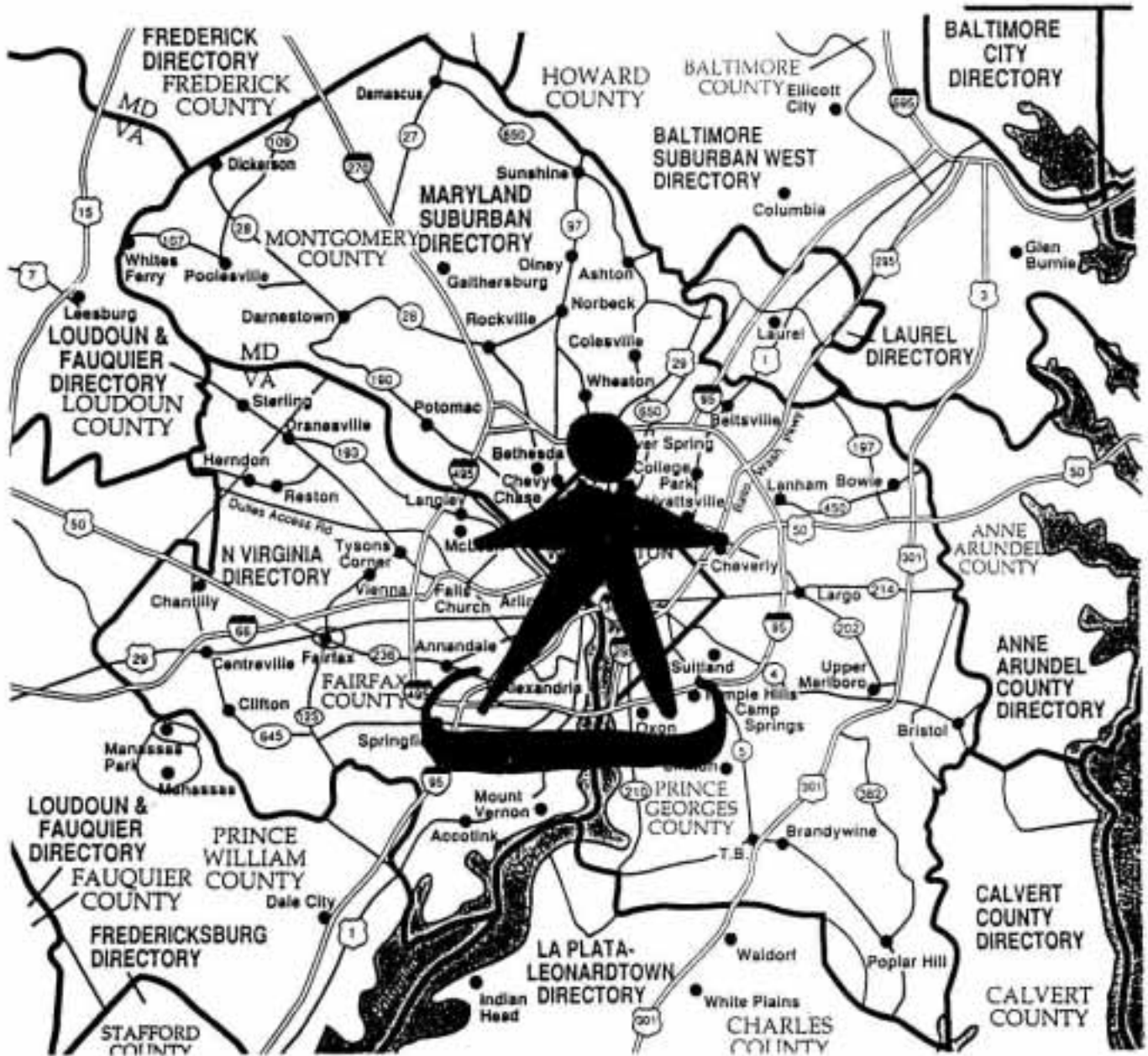
RE: Staff turnover

3. Provides some accountability for outcomes.
Are we making a difference?

RE: Effective use of public funds

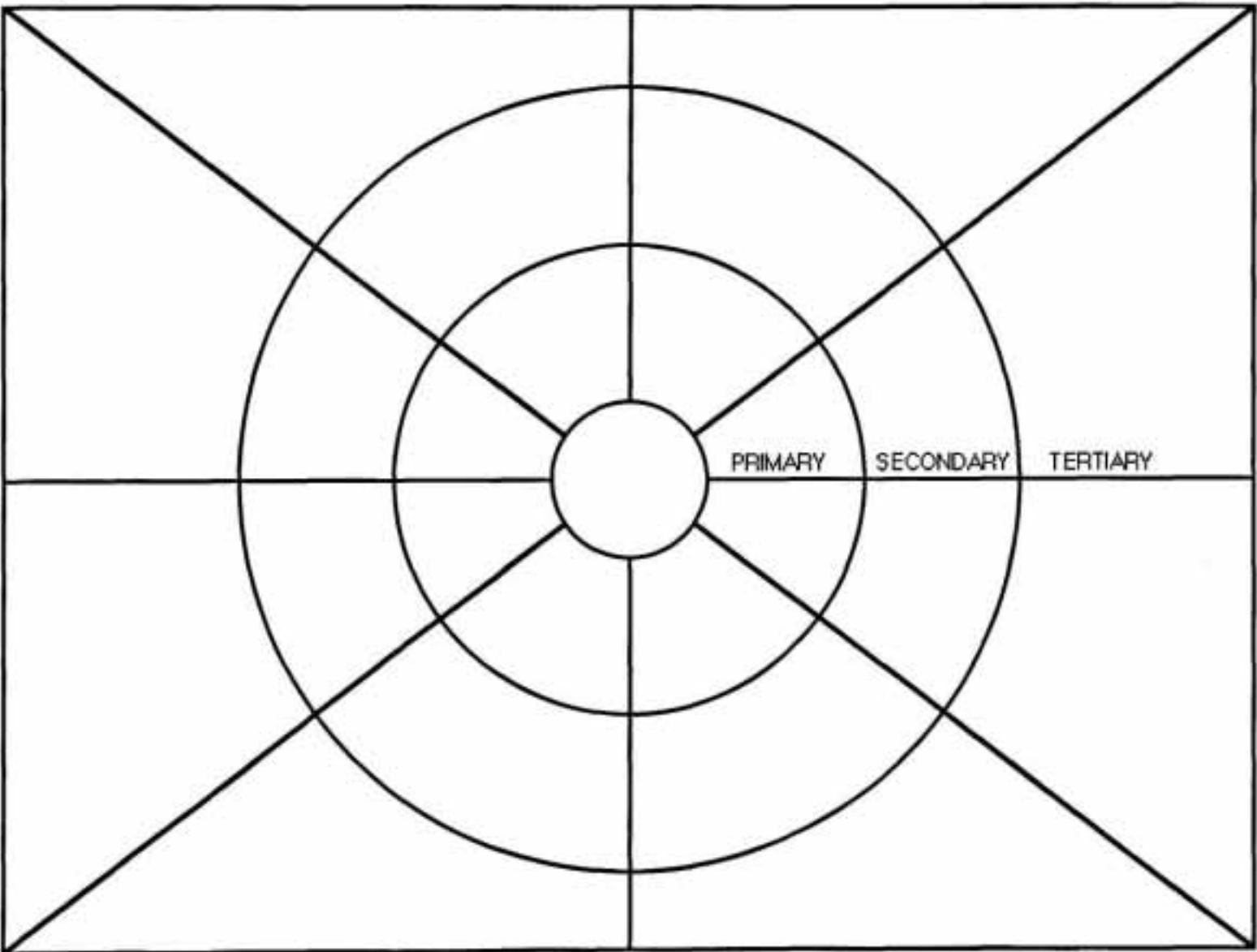
"MAPPING"

(Based on the work of Beth Mount)



Finding our way to a personal lifestyle...

Relationship Map



PLACES

PERSONAL HISTORY

PREFERENCES

CHOICES

CAPACITIES

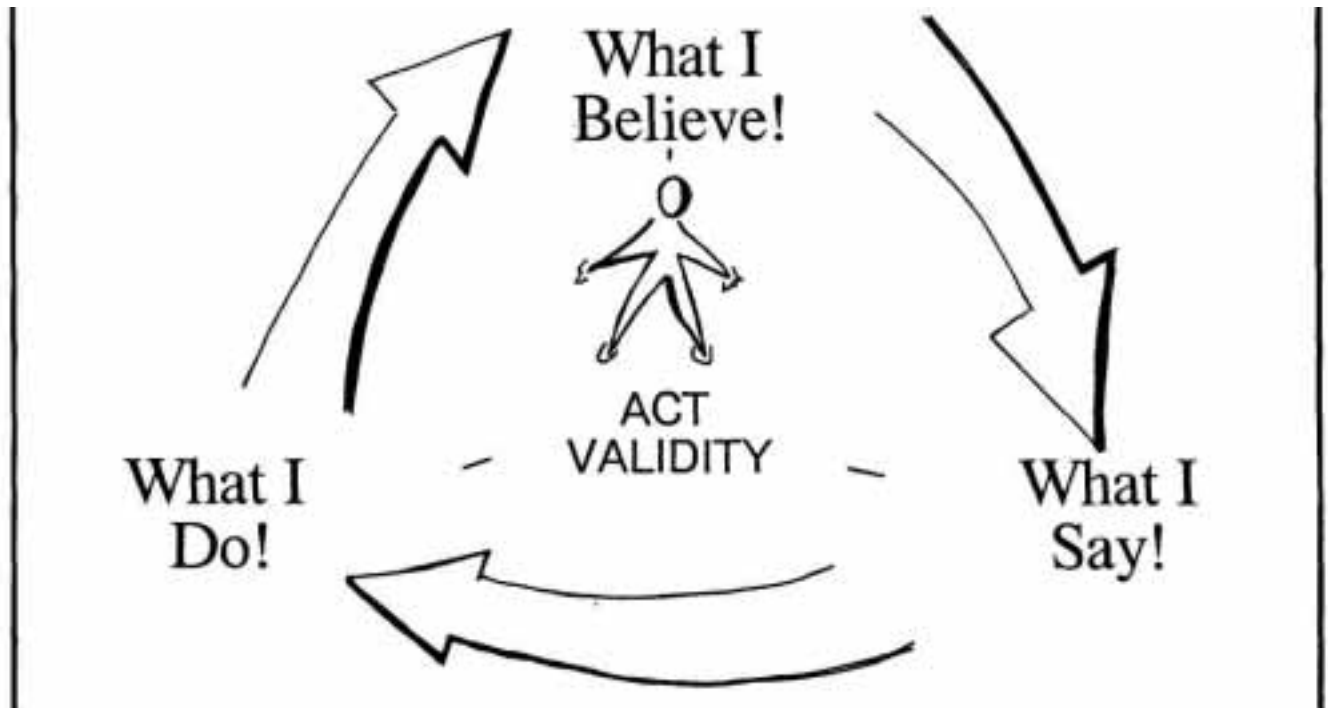
DREAMS

If the dream is to be,
what needs to happen now?

What?	Who Will Help?	By When?

GOING BACK TO WORK

- *WORKING with MORAL COHERENCY...* -



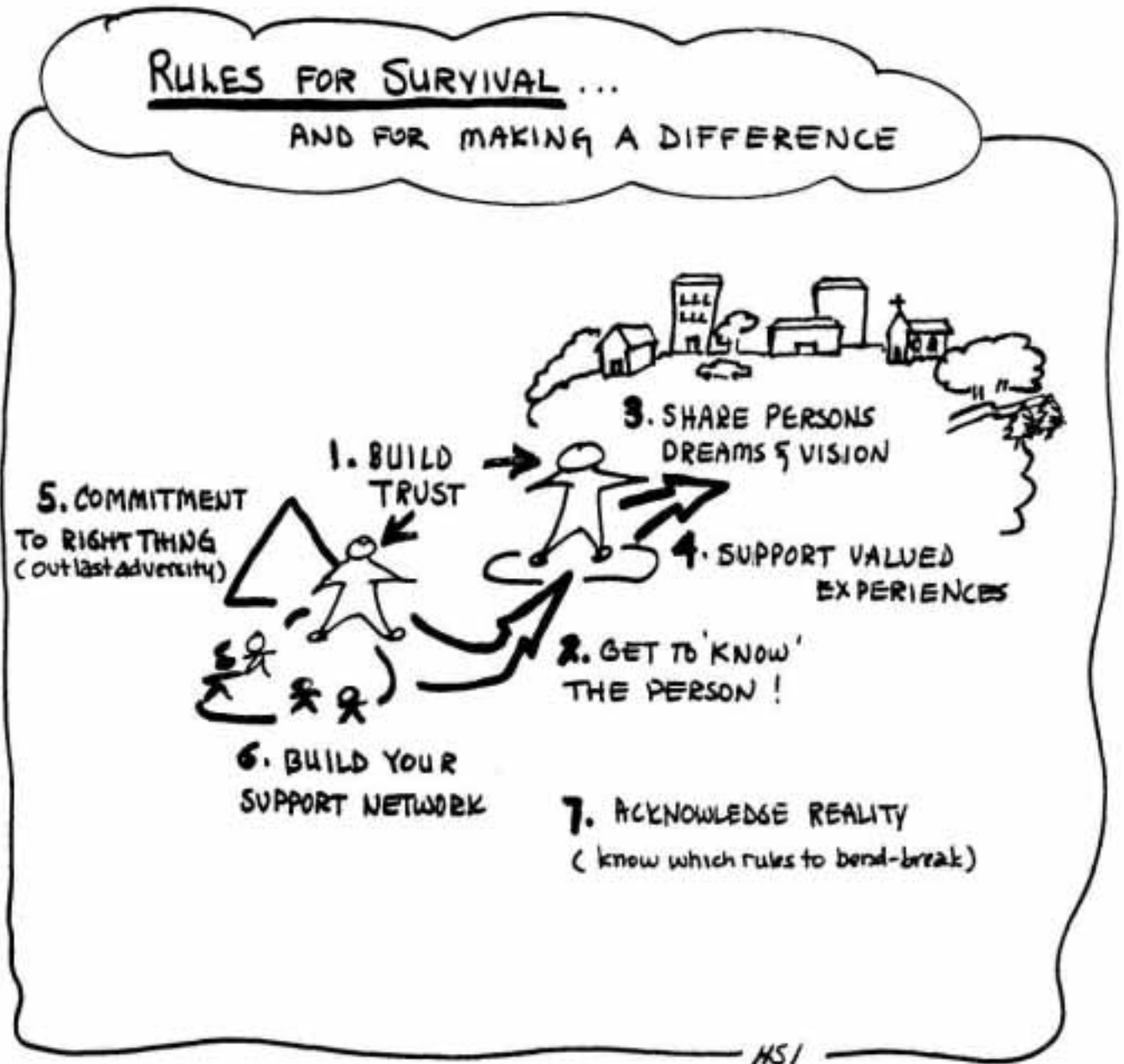
In a DYSFUNCTIONAL SERVICE SYSTEM

NOTES:

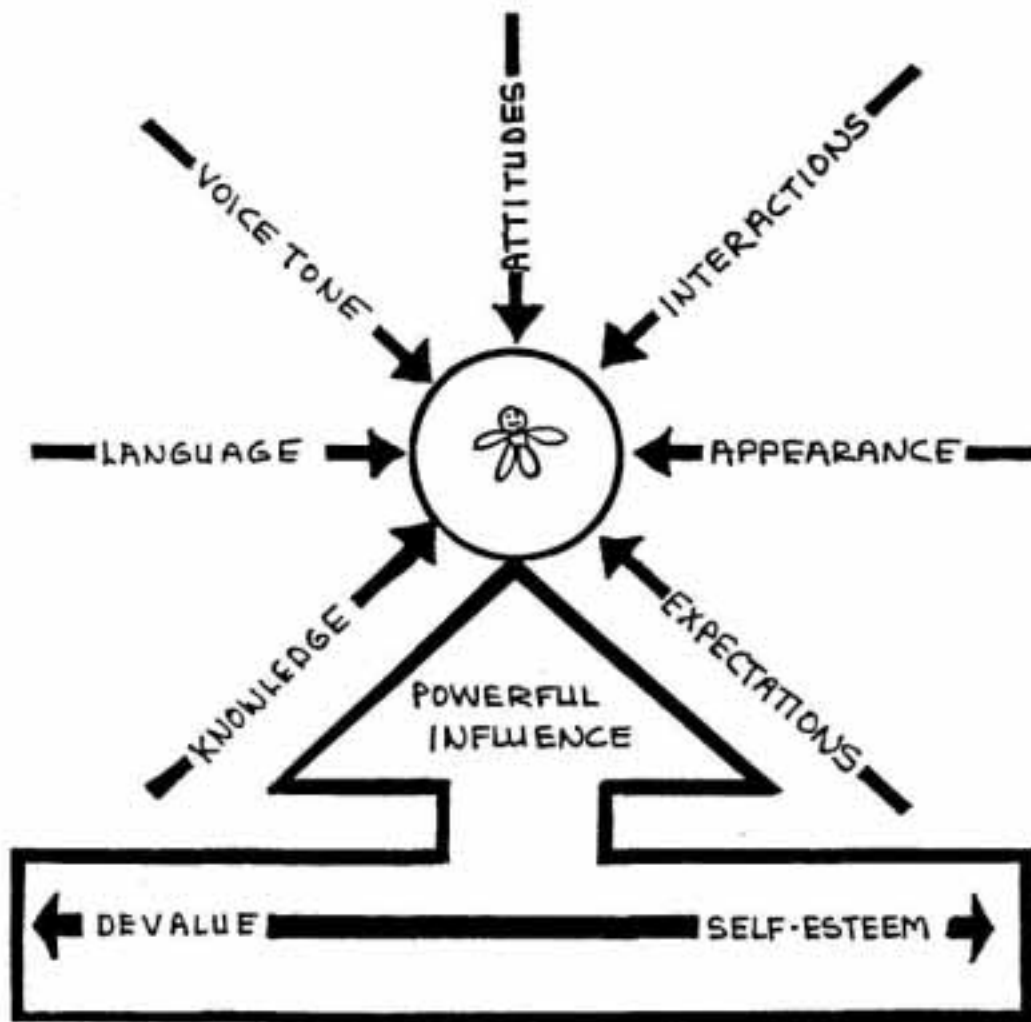
What I Believe

What I Say

What I Do



Staff as... ROLE MODEL



REMEMBER: You are one of the most important and influential people in the life of the consumer !

Pathways to Excellence

Personal Reflections to Help You Return to Work

1. List one major issue or decision that will be your focus for change or influence in the agency/program with which you are involved.

a. What are the obstacles to this change?

b. What are the opportunities to support this effort?

2. Think about one person served (client) you work with. What is your vision of how life could be different, better, more community focused for that person?

a. What opportunities & supports will help accomplish this?

b. What obstacles will get in the way?

3. What do you hope to do differently in your personal work as a result of the Pathways Training?

4. Other notes or comments.

EVALUATION

Date:

Mo _____ Yr _____

Agency _____
(Optional)

INSTRUCTIONS: Please rate the Pathways training accurately and honestly. Your feedback will help us to make improvements to insure training of the highest quality.

RATING SCALE: 1 POOR 2 ACCEPTABLE 3. GOOD 4 EXCELLENT

FACTORRATING BY SESSION

1. Training Content?
(Relevance, Interest, Importance)
2. Presentation of Content?
(Overheads, Exercises, Printed Material)
3. Quality of Trainer Interactions?
(Encouraged participation, response to questions)
4. Relevance of Content to Your Job?
(Will training enhance your skills and knowledge?)
5. Organization and Delivery?
(Was material clear, well organized?)

SESS I	SESS II	SESS III

TOTAL SCORE

COMMENTS

1. Which sessions or topics were most beneficial? Why? _____
2. Which sessions or topics were least beneficial? Why? _____
3. What changes would make the training better? _____
4. Additional Comments _____